

Running Head: Team versus single practitioner diagnostic experience.

A Multidisciplinary Team versus Single Practitioners:
Parental Satisfaction and Wait in the Autism Spectrum Disorder Diagnostic Experience

by

Lynn Laverdière-Ranger

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APPROVED/APPROUVÉ

Thesis Examiners/Examineurs de thèse:

Dr. Cynthia Whissell
 (Supervisor/Directrice de thèse)

Dr. Shelley Watson
 (Committee member/Membre du comité)

Dr. Terri Barriault
 (Committee member/Membre du comité)

Dr. Lynn Martin
 (External Examiner/Examinatrice externe)

Approved for the School of Graduate Studies
 Approuvé pour l'École des études supérieures
 Dr. David Lesbarrères
 M. David Lesbarrères
 Director, School of Graduate Studies
 Directeur, École des études supérieures

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ABSTRACT

This is a mixed-methods study investigating parental satisfaction and wait times as parents inquire about an autism spectrum disorder diagnosis for their child in a Northern Ontario community. Satisfaction and wait times of those diagnosed with an autism spectrum disorder (ASD) by a single practitioner were compared to satisfaction and wait times of those diagnosed by the multidisciplinary assessment team in the Sudbury/Manitoulin region (the Autism Diagnostic Team; ADT). No significant differences were noted between groups on satisfaction or wait times. However, ADT group received much more consistent service, with less variation in wait times between clients, and more consistent provision of comprehensive services prior to the diagnostic meeting. Points of interest are noted for practitioners including increased wait times for parents of children with milder forms of ASD and for girls. No differences in wait time or satisfaction were noted between language groups. Content analysis of the qualitative interviews representing mainly single practitioners saw the emergence of themes including difficulty activating the assessment process, concerns regarding the wait, and appointment demands. The importance of professional expertise, empathy, and respectful communication also emerged. Parents felt the experience was deeply distressing and they often experienced abandonment following the diagnostic process. Additionally, parents whose children did not receive a diagnosis often felt confusion about what to do next. Reducing wait times, increasing professional expertise, completing comprehensive assessments, and using truly interdisciplinary teams should continue to be the focus of service improvements that may translate into improved satisfaction.

Keywords: autism, ASD, multidisciplinary assessment teams, interdisciplinary assessment teams, assessment process, parental satisfaction, wait time.

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TABLE OF CONTENTS

Abstract.....	iii
Acknowledgements.....	iv
Table of Content.....	v
List of Tables.....	viii
List of Figures.....	ix
Chapter I: Review of the literature	1
Autism Spectrum Disorder.....	1
Impact of seeking a diagnosis of Developmental Disability on parents.....	2
Impact of the ASD diagnostic process on parents.....	3
Parental Stress.....	4
Service implications.....	5
Best practice in diagnosing ASD.....	6
Interdisciplinary versus multidisciplinary.....	7
The effectiveness of a diagnostic process involving a team.....	7
History of diagnostic services in Sudbury.....	10
Reflexivity.....	14
Statement of the problem.....	15
Research Objectives.....	16
Chapter II: Methods.....	17
Participants	17
Description of the sample.....	19
Measures.....	21
Demographic measures.....	23
Wait times.....	23
Satisfaction.....	24
Child clinical data.....	24
Qualitative component.....	25
Procedures.....	26

Ethical considerations.....	29
Use of an Assistant.....	30
Chapter III: Results.....	31
Wait Times.....	31
Satisfaction.....	32
Point of interest for practitioners.....	33
Comprehensiveness of the assessment.....	33
Differences based on demographic variables.....	35
Marital Status and Income.....	35
Language.....	35
Differences based on child specific and clinical data.....	36
Gender.....	36
Severity of diagnosis.....	36
Summary of the quantitative findings.....	38
What is the diagnostic experience?.....	38
Overview of themes.....	40
The process and associated feelings.....	42
Difficulty activating the process.....	42
Concerns regarding the wait.....	44
Appointments demands.....	46
Reactions to professionals and associated feelings	46
How well professionals listened.....	47
Share your knowledge but be kind.....	48
Professional expertise.....	49
Feelings relating to the diagnostic outcome.....	50
Deep distress.....	50
Perceived abandonment	52
Evidence of coping.....	53
Emerging agency.....	53

Feeling gratitude.....	54
Acceptance and support.....	54
Non diagnosis.....	55
Summary of the experience shared by participants in this study.....	56
Chapter IV: Discussion.....	58
A more consistent experience.....	58
Enduring feelings and experiences.....	60
The mixed-methods message regarding the ADT.....	61
The type of team: An important difference to consider.....	62
Lessons learned from different diagnostic paths.....	63
Strengths and limitations of the study.....	67
Validation procedures.....	69
Recommendations for practice.....	71
Empathetic and knowledgeable professionals.....	71
Improved parental awareness.....	73
Post-diagnostic support.....	73
Parental suggestions.....	74
Future Research.....	75
Conclusion.....	76
REFERENCES.....	78
Appendix A: Questionnaire.....	83
Appendix B : Parent Consent Form.....	86
Appendix C : Introductory Letter.....	87
Appendix D: Ethics Approval: Laurentian University	88
Appendix E: Summary of Themes.....	89

LIST OF TABLES

Table 1: Diagnosis by Group.....	19
Table 2: Child Clinical Data.....	21
Table 3: Demographic Information – Parent/Guardian.....	22
Table 4: Standard Deviations by Group.....	32
Table 5: Comprehensiveness of Initial Diagnosis by Category of Cognitive Ability.....	34
Table 6: Comprehensiveness of Initial Diagnosis by Type of Practitioner.....	34
Table 7: Wait Time Ranks by Gender.....	36
Table 8: Mean Rank for Wait time to specificity by diagnosis.....	37
Table 9: Mean Rank for Wait time by IBI Eligibility.....	37
Table 10: Information on Participants for Qualitative Interview.....	39

List of Figures

Figure 1: ADT Process.....	12
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Chapter I: Review of the Literature

This chapter will explain autism spectrum disorders and provide an overview of the literature on parental reactions to the diagnostic process. The literature on the effectiveness of team-based diagnostic processes will then be reviewed. Next, a review of best practice in diagnosis will be presented followed by a brief history of diagnostic services in the Sudbury region. Given the mixed-methods nature of this study, the principal researcher's experiences working with children and families dealing with a new diagnosis of Autism Spectrum Disorder for their child will be presented in the reflexivity section of this chapter. Finally, the statement of the problem and research objectives will be presented.

Autism Spectrum Disorder

Autism Spectrum Disorder (ASD) is a developmental disability characterized in the Diagnostic and Statistical Manual – 5th edition (DSM-5) by “persistent deficits in social communication and social interaction across multiple contexts” (American Psychiatric Association, 2013, p.50). These deficits may manifest through difficulty with social-emotional reciprocity, nonverbal communication, and difficulty creating and/or maintaining relationships. Additionally, in order to obtain a diagnosis of ASD, a child must manifest symptoms early in life that include “restricted, repetitive patterns of behavior, interests, or activities”(American Psychiatric Association, 2013, p. 50). Severity levels are provided to help indicate the individual's level of impairment. Prior to the release of the DSM-5 in 2013, autism spectrum disorders, which had previously been referred to as pervasive developmental disorders, formed a diagnostic category covering a range of disorders. They included autistic disorder (autism), Asperger's disorder, and pervasive developmental disorder, not otherwise specified (PDD-NOS;

atypical autism). This diagnostic category was characterized in much the same way it is today; by varying degrees of qualitative impairments in social interaction, communication, and repetitive, stereotyped patterns of behaviour and interest (American Psychiatric Association, 2000). The prevalence rate of autism spectrum disorders in Canada has been rising and is currently estimated at between 1 in 143 to 1 in 167 children (Fombonne, 2009; Saracino, Noseworthy, Steiman, Reisinger, & Fombonne, 2010). Boys are four times more likely to receive a diagnosis of ASD than girls (Fombonne, 2009).

All physicians in Canada have the right to diagnose a child with an ASD. Additionally, psychologists and psychological associates are permitted to diagnose this disorder. Children suspected of having an ASD may additionally consult occupational therapists, physiotherapists, audiologists, dieticians, educational specialists and speech language pathologists. Although these professionals may identify symptoms of ASD, they are not permitted the act of diagnosis (Nachshen et al., 2008).

Impact of Seeking a Diagnosis of Developmental Disability on Parents

Receiving any diagnosis of developmental disability for your child has great implications and a large impact on parents (Estes et al., 2009; Goin-Kochel, Mackintosh, & Myers, 2006; Miodrag & Hodapp, 2010; Watson, 2009). Watson, Hayes, & Radford-Paz (2011) provided a review of the research about the impact of seeking a diagnosis of developmental disability on parents. They noted that parents often seek a diagnosis of developmental disability for various reasons ranging from wanting to understand their child better and accessing special services to gaining prognostic information such as expected behavioural presentations and life expectancy. Parents also reported seeking a diagnosis to determine etiology. When seeking a diagnosis of developmental disability, Watson et al. (2011) noted recurring stressors in the literature: the

number of professionals seen, wait times, lack of knowledge of a specific disability, and the manner in which professionals communicate sensitive information to parents. Furthermore, the point at which an assessment was completed and results shared with the family was in and of itself impactful as families experienced grief at the loss of normalcy, relief at finally receiving a diagnosis, or stress and uncertainty in the event of a non-diagnosis.

Impact of the ASD Diagnostic Process on Parents

Goin-Kochel et al. (2006) surveyed 494 parents (mainly mothers from the United States) whose children had received a diagnosis of ASD to examine parental satisfaction with the diagnostic process and the age at which their children were diagnosed as well as determine if any demographic variables were related to this satisfaction. Satisfaction was measured with one question asking whether they were extremely satisfied, moderately satisfied, or not satisfied. The researchers found that the average age of diagnosis for the children in the sample was 4.5 years (3.4 years for autism, 7.5 years for Asperger's disorder), with a standard deviation of 2.9 years, and a range between 0.8 and 15.3 years. However, the age at diagnosis differed according to the diagnosis itself. Children receiving a diagnosis of Asperger's disorder or PDD-NOS were diagnosed later than those receiving a diagnosis of autism, and children diagnosed with Asperger's disorder received that diagnosis later than children who received a diagnosis of PDD-NOS. The researchers also noted that girls were diagnosed at a later age than boys when the diagnosis was Asperger's disorder and PDD-NOS. The more professionals a child saw, the older he or she was when diagnosed. Parents reported the most satisfaction with the diagnostic process when they had seen fewer professionals (consecutively) and when the child was diagnosed earlier.

Osborne and Reed (2008) conducted fifteen focus groups in the United Kingdom to gain

insight into parents' perceptions of the diagnostic process and to garner ideas on how to improve the process. Parents were grouped according to their children's age. All children were reportedly diagnosed by a single professional; either a medical professional, a psychologist, or a speech language pathologist. When asked what they found helpful about the diagnostic process, 50% of preschoolers' parents found nothing helpful. When asked what could have been improved about the diagnostic process, 27% of parents felt that more prognostic information (i.e., the expected long term outcome) would have improved their experience. Additionally, 25% wished for standardized testing and faster assessment, 24% of parents thought they would have needed information about services and organizations available to them, and 18% would have liked offers of support and help. When asked when this information would be most helpful, 84% of parents of preschool children reported wanting this information at the time of diagnosis. Parents wished for a faster and easier process along with a clearer structure, and more content. They sought greater professional knowledge and awareness of ASD, as well as a greater focus on the development of professionals' interpersonal skills.

Despite this process being difficult for parents, they continue to seek a diagnosis. In their synthesis of the research, Watson et al. (2011) conclude that "receiving a diagnosis may be the key to restoring family functioning following a period of crisis associated with the challenging behaviors related to an undiagnosed disability" (p.57). Furthermore and specific to parents of children with an ASD, they seek a diagnosis in order to access behavioural services and financial support.

Parental Stress

With the behavioural challenges associated with ASD, receiving this type of diagnosis may be particularly stressful on these parents (Goin-Kochel, Mackintosh, & Myers, 2006;

Osborne & Reed, 2008; Watson, 2009). A recent meta-analysis completed by Hayes and Watson (2013) examined the state of the literature on the topic of parental stress comparing parents of children with ASD, other developmental disabilities, and typically developing children. The results of the meta-analysis supported the notion that parenting a child with ASD is more stressful than parenting a typically developing child with an effect size of 1.58 based on a random-effects model, which constitutes a large effect. Furthermore, when comparing parenting stress of parents of children diagnosed with ASD to that of parents whose children were diagnosed with other developmental disabilities, the combined studies indicate that the ASD group experienced greater stress levels, with an effect size of 0.64. Parents with a child who has a diagnosis of ASD are more likely to report physical or mental health issues (Miodrag & Hodapp, 2010). As well, once children have received a diagnosis and are in treatment, children of parents with high levels of stress are less likely to benefit from intensive treatment (Osborne, McHugh, Saunders, & Reed, 2008). Therefore, reducing parental stress may be one way of improving how well the child will react to treatment.

Service Implications

A variety of services are offered to children once they obtain a diagnosis of ASD. These services vary in intensity depending on the needs of each individual child, and many involve access to applied behaviour analysis (ABA). Applied behaviour analysis is defined as “the science in which tactics derived from the principles of behavior are applied systematically to improve socially significant behavior and experimentation is used to identify the variables responsible for behavior change” (Cooper, Heron, & Heward, 2007, p.20). ABA has been proven an effective treatment for autism spectrum disorders (Alberto & Troutman, 2008; Baer, Wolf, & Risley, 1968; Cooper, Heron, & Heward, 2007; Lovaas, 1987; McEachin, Smith, &

Lovaas, 1993). Due to the evidence regarding its effectiveness, Ontario schools are required to provide access to services based on the principles of ABA (Ministry of Education, 2012).

Furthermore, children at the more severe end of the autism spectrum may be eligible for the autism intervention program, commonly referred to as Intensive Behavioural Intervention or IBI (Ministry of Children and Youth Services, 2010a). IBI is a direct-service, 20 to 35 hours per week treatment program based on the principles of applied behaviour analysis. The IBI program is often highly sought after by parents of young children with a diagnosis of ASD due to the success that was noted by its founder, Ivar Lovaas. In the initial Lovaas study (1987), 40 hours per week of direct service over the course of two years resulted in a 47% recovery rate. The Lovaas study showed parents the possible benefits of early and intensive intervention.

Best Practice in Diagnosing ASD

Given the implications of a diagnosis of ASD, early and appropriate identification of the disorder is paramount. In the Miriam Foundations' Diagnostic Guidelines, Nachshen et al. (2008) wrote that "best practices refer to the measures, techniques and methods that have been demonstrated to be valid and reliable through scientific research and/or have been agreed upon by a committee of scientific experts and experienced clinicians, with input from active clinicians and parents" (p. 10). Nachshen et al. (2008) indicated, among other things, that it was best practice in the diagnosis of autism spectrum disorders to use interdisciplinary teams consisting of speech language pathologists, pediatricians, psychologists, and occupational therapists. This approach is considered beneficial because it incorporates information from various perspectives, allowing a broader understanding of the child's strengths, weaknesses, and abilities. This best practice document was a synthesis of commonly existing recommendations that were summarized and reviewed by the panel, which then determined what would be considered best

practice (p. 12). From the parents' perspective, an interdisciplinary approach was most appreciated in helping them understand and come to terms with the diagnosis (Nachshen et al., 2008, p.43).

Interdisciplinary versus multidisciplinary. Although interdisciplinary teams are recommended as best practice based on the definition provided by Nachshen et al. (2008), multidisciplinary teams also exist. Nachshen et al. (2008) explains that an interdisciplinary team “involves the integration and synthesis of information gathered by professionals of different disciplines, through an interactive group process” (p.11). A multidisciplinary team, on the other hand, relies on information provided by multiple different types of professionals working mostly independently from one another. Professionals independently come to their own conclusions without getting input from other team members. This approach is therefore less integrated and possibly less coordinated than what might be seen in an interdisciplinary team (Nachshen et al., 2008, p.11).

The Effectiveness of a Diagnostic Process Involving a Team

Two studies on the effectiveness of a team approach to diagnosis were identified by the principal researcher. The first, by Helen Kerrell (2001), studied the effectiveness of a multidisciplinary team, while the second, by Beatson and Prelock (2002) studied an interdisciplinary team. The results of both studies are presented below.

Kerrell (2001) completed a service evaluation of an autism multidisciplinary diagnostic clinic by investigating the experiences of parents whose children had received an assessment through the clinic, located in the United Kingdom. Parental satisfaction was the main variable being investigated. Researchers were also interested in discovering the needs of this population in regards to the assessment process. Eleven families (ten mothers and one father) completed

approximately a one-hour face-to-face interview in their homes. Nine of the children were diagnosed with autism while two were diagnosed with Asperger's disorder. The average age of the children was 3.7 years. The researcher used a four-point rating scale to measure satisfaction along with two open-ended questions: "How could the service be improved for you and your child?" (Kerrell, 2001, p.34), and "Additional comments" (Kerrell, 2001, p. 35). The majority of clients reported poor satisfaction with their service. The following themes were noted in the open-ended questions: lack of information, the need for ongoing support following the diagnosis, clarity around professional roles, more time spent in assessment, and unfulfilled expectations regarding the clinic's service (Kerrell, 2001). Overall, their results were consistent with the general experience of receiving a diagnosis of ASD from single practitioners.

Beatson and Prelock (2002) examined the effectiveness of an interdisciplinary assessment model in Vermont (The Vermont Rural Autism Project; VT-RAP) that was structured around three key theoretical frameworks: family-centered care, cultural competence, and the strengths perspective. The VT-RAP dynamic assessment process offered in-place professionals from twelve disciplines, followed by the provision of appropriate interventions (Prelock, Beatson, Bitner, Broder, & Ducker, 2003). Upon referral, families would complete eight steps in the VT-RAP assessment process (Prelock et al., 2003):

- 1) assignment of an assessment coordinator;
- 2) in-depth, in-home interview with the coordinator;
- 3) preassessment planning meeting with the family and the entire team, including community members to plan the assessment;
- 4) assessments by interdisciplinary team members the family had met in the pre-assessment planning meeting;

- 5) post-assessment planning meeting with all team members and the family to review the results, discuss possible intervention strategies, and set priorities;
- 6) completion of a draft report reviewed by the parents and all stakeholders;
- 7) follow-up meeting to review the report, share recommendations with the community, and create a plan for implementation of recommendations;
- 8) resource binder shared with the family and community service providers.

(p.196)

The qualitative portion of the study asked nine parents (mostly mothers) a set of three questions: “(a) What were the parents’ experiences having their child assessed through VT-RAP? (b) What happened as a result of participating in the community-based assessment? and (c) What recommendations do parents have for improving VT-RAP’s assessment process?” (Beatson & Prelock, 2002, p.49). Parents completed interviews lasting between one and one and a half hours. The children ranged in age from 3 years 9 months to 10 years. Two of the children had not received a diagnosis of ASD following their assessment. Data were coded and categorized in themes, tales, and poetic transcription through a process that involved “reading the transcripts and grouping similar statements that eventually became categories and then themes.” (Beatson & Prelock, 2002, p. 49). In regards to the continuum of services offered at the clinic, an overall theme of shifting attitudes emerged, as well as three additional themes. The ‘Getting Enrolled’ theme reflected the parents’ increased engagement with services as a result of the VT-RAP team. The ‘Becoming Friends’ theme reflected parents’ acknowledgement regarding the relationships they fostered with other parents and with professionals on the team. Finally, the ‘Empowerment and Transformation – Having Something to Hang on to’ theme reflected the families’ appreciation for the resources they had access to during and following the assessment,

particularly a resource binder that was provided to each family following diagnosis. The study revealed a positive impact of service provision resulting in reports reflective of empowerment:

The families interviewed felt they were seen as families, received unbiased information, gained access to expertise and knowledge, and were actively listened to and included in the team. These experiences contributed to parents' feeling empowered (Beatson & Prelock, 2002, p.53)

History of Diagnostic Services in Sudbury

Between 2007 and January 2010, the service delivery model in Sudbury included multiple practitioners and waitlists. Local pediatricians primarily diagnosed children following the disbanding of a local developmental services agency (Developmental Clinical Services – DCS) in 2007, which had been responsible for conducting diagnostic assessments along with pediatricians in the area (Child and Community Resources, CCR History, 2013). Speech language pathologists often referred children to the pediatricians after children had been flagged for their services due to language delays. Of course, prior to being seen by the Speech language pathologist, families waited on wait lists for this service (Renaud, Little, & Stafford, 2011). Local speech language pathologists and pediatricians do not offer ABA interventions that are considered best practice in treatment for these families. Therefore, this community service model resulted in yet another referral and another waitlist at Child and Community Resources (CCR; formerly Child Care Resources) for Autism Clinical Services (ACS). The combined wait time was estimated at 28 months, with wait times calculated based on direct report by community service providers and the centralized referral agency based on the date parents presented for

service (T. Barriault, personal communication, February 2010). Wait times prior to the disbanding of DCS are unavailable.

In 2010, the Autism Diagnostic Team (ADT) began diagnosing children up to 6 years of age in the Sudbury/Manitoulin region upon referral from parents or other professionals (see figure 1). Children over six continued to be referred to their pediatrician. At the time this study was underway, the ADT used well-trained multidisciplinary professionals following DSM IV-TR criteria, gathering diagnostic information from multiple sources. Prior to the Autism Diagnostic Observation Schedule (ADOS) testing that would occur in an interdisciplinary environment, all children on the list would have at minimum completed a speech-language assessment to gain an understanding of the child's language ability, and a medical assessment with a pediatrician to rule in or out other possible diagnoses. Additionally, children received a psychological assessment of cognitive and adaptive functioning. The psychological assessment followed a family-centered approach similar to that articulated by Dunst and Trivette (cited in Beatson & Prelock, 2002) "that (a) requires that care providers are empathic, caring, warm, and excellent listeners; (b) sees the strengths of parents and believes that parents can gain expertise; and (c) actively engages parents in the process in a deep and meaningful manner"(p.53). During the psychological assessment, which would form the basis of the final assessment report, autism specific testing using standardized measures such as the Autism Diagnostic Interview – Revised (ADI-R) or the Childhood Autism Rating Scale (CARS) may have also been completed in order to support any future diagnosis.

Once the multidisciplinary assessments were completed, the team, at times the same professionals and at times different professionals previously seen by the family, gathered to

complete an Autism Diagnostic Observation Schedule (ADOS) and to review the entire case prior to coming to a decision regarding the presence or not of an autism spectrum diagnosis.

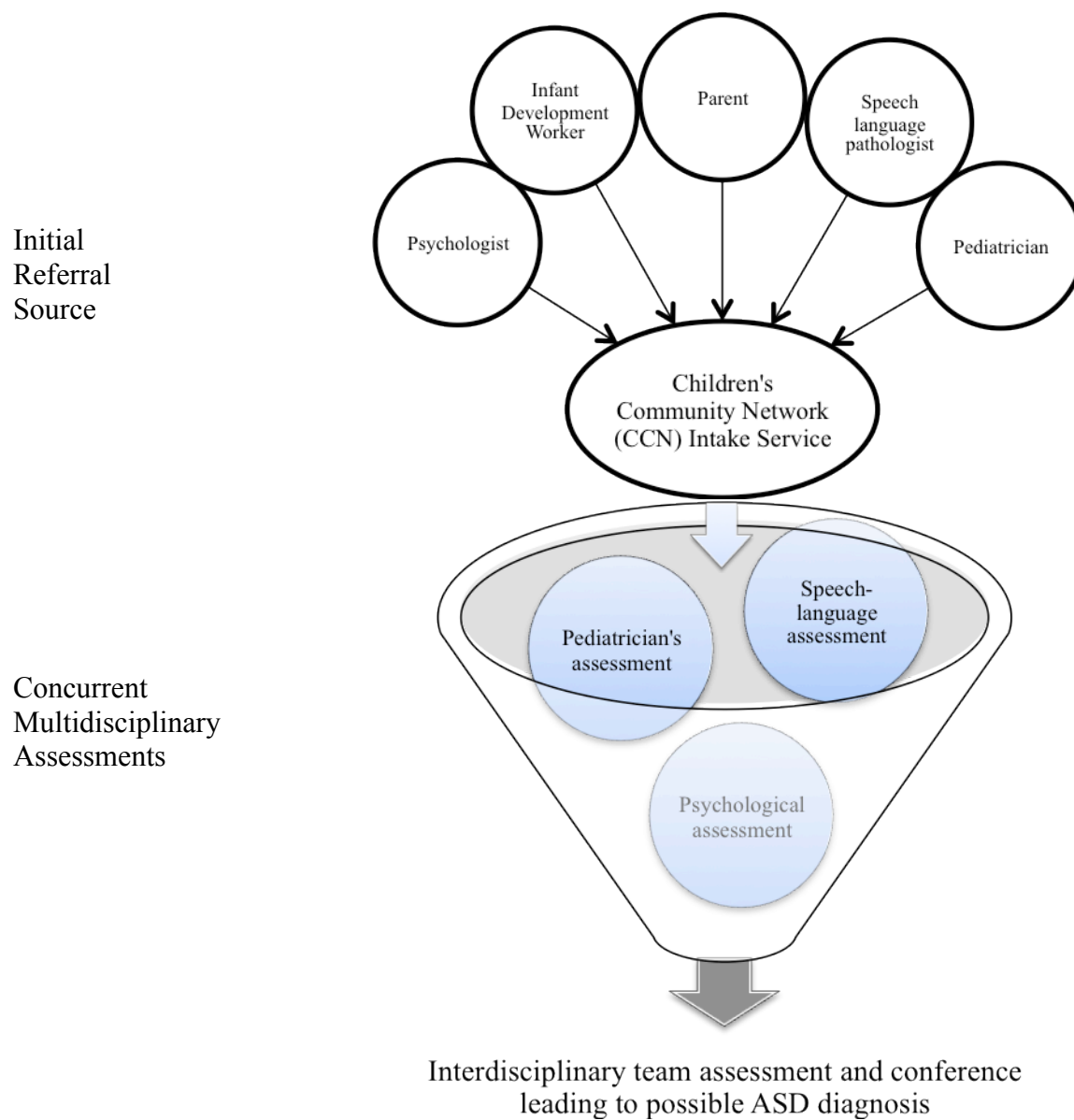


Figure 1: ADT process

The parents would meet and interact with the professional administering the ADOS, but they would not meet the entire diagnostic team, who watched the assessment in a separate room via live video-feed. The parents were made aware of this assessment set-up. As had always been the case following assessments at CCR, assessments leading to diagnosis were followed up with a comprehensive feedback meeting with the supervising psychologist to review results of the report, share the diagnosis, discuss prognosis and available services, and answer parents' questions. In situations when no diagnosis was provided, the psychometrist independently shared the results of the assessment with the family. Parents left the diagnostic assessment feedback meeting with a copy of the report, and copies were sent to all professionals involved with the child, with parental consent. Furthermore, as an official provider of French-language services, CCR attempted to offer services in both official languages as needed.

The ADT had four goals. They aimed to reduce wait times, to maintain or increase the number of children served, to increase the community's professional capacity and knowledge about ASD, and to establish community and parental satisfaction with the diagnostic service. In order to increase the community's professional capacity, the monthly clinic was opened for students and professionals to come and learn about the ADOS through observation of the assessment and subsequent consensus scoring. The ADT received a 2009 Innovative Access to Psychological Services Award from the Canadian Psychological Association Foundation. In August 2011, the ADT secured funding to help improve access to services for Francophone minority communities in the Sudbury/Manitoulin district for children under six and their families dealing with a possible diagnosis of ASD through *Société Santé en français (SSF)* and Health Canada. "This is a psychological service typically conducted by a Psychometrist under the supervision of a Clinical Psychologist. Community based Speech-Language Pathologists and

Pediatricians collaborate as part of the team” (Child and Community Resources, Intensive Behaviour Intervention (IBI), 2013).

Reflexivity

Because of the subjective nature associated with using interviews in qualitative studies, there is some concern that interpretations and themes that emerge from the data are nothing more than self-fulfilling prophecies related to the researcher’s own beliefs. Reflexivity is a process by which the researcher attempts to minimize the impact of his or her own experiences, thoughts and beliefs on the outcome of the study. “Reflexivity benefits research through facilitating a critical examination of how the researcher interacts and influences data” (Newton, Rothlingova, Gutteridge, LeMarchand, & Raphael, 2012). Creswell (2007) defines reflexivity as the researcher’s consciousness of “biases, values, and experiences that he or she brings to a qualitative research study” (p.244). The following section includes information about the principal researcher’s experiences working with this population that may have an impact on the analysis and interpretation of data.

Many assessments completed at Sudbury’s CCR at the point of assessment to determine eligibility for intensive services between 2007 and 2009 (prior to conceptualization of the diagnostic team) were performed by the principal researcher for this study along with a Registered Clinical and School Psychologist, also a committee member for this thesis. The principal researcher had worked with families and children dealing with a diagnosis of ASD between 2007 and 2012. Prior to this work experience, the principal researcher had worked in a school setting completing psychoeducational assessments for eight years. While working as a psychometrist for a local French public school board between 1999 and 2004, the principal

researcher participated on community-based committees dealing with the issues facing families with ASD as well as training needs of educational assistants within school-boards.

Given that CCR supports a family-centered approach, the families' concerns, when voiced, were attended to by this researcher. Anecdotal parental reports were quite consistent across parents who experienced high levels of stress related to the lack of access to support at the time of diagnosis, waited on multiple wait lists, and were uncertain about the prognosis and supports available to them. Parents frequently noted that they had to figure things out for themselves and that they were uncertain about the validity of the diagnosis they received from a physician during a short appointment. Parents often mentioned having difficulty accepting the diagnosis and also reported they had lacked information about the disorder at the time of diagnosis. This anecdotal information was consistent with what had been determined to be the experience of other parents of children with Autism Spectrum Disorders during the diagnostic process (Osborne & Reed, 2008; Watson, 2009). It therefore represents what the principal researcher expected to find as a result of the study.

It was the parents' dissatisfaction along with knowledge and referral to the Best Practice Guidelines document that led to the conceptualization and eventual development of the ADT community-based team by the principal researcher and her clinical supervisor. In embarking on this study, the principal researcher also expected that families who followed this new streamlined process would be more satisfied and wait less than families who completed the assessment process prior to the development of the ADT.

Statement of the Problem

Interdisciplinary teams are considered best practice as a result of agreement between experienced clinicians in the field of autism (Nachshen et al., 2008). A part interdisciplinary,

part multidisciplinary team that will be referred to as a multidisciplinary team has been implemented in the Sudbury/Manitoulin region. However, no research was found that compared interdisciplinary or multidisciplinary assessments with assessments completed by a single practitioner. Thus, although a team diagnostic service is considered best practice, there is relatively little scientific evidence that such practice is effective or experienced as beneficial. Additionally, we know very little about the experience of receiving a diagnosis from a multidisciplinary team in Canada.

Research Objectives

This study asked parents' opinions in the service of two main objectives. The first objective of this study was to partially determine the effectiveness of the multidisciplinary assessment team at CCR by examining two of the ADT's objectives: wait times and parental satisfaction. The following hypotheses were tested:

1) Hypothesis one: Wait times will be smaller for the ADT group compared to single practitioners.

2) Hypothesis two: The group diagnosed by the ADT will report higher levels of satisfaction overall than parents whose child was diagnosed by a single professional.

The second objective of the study was to gain a better overall understanding of the experience of going through the diagnostic process and to glean whether parents who received a diagnosis by the ADT reported different experiences than parents who received a diagnosis elsewhere.

Chapter II: Methods

This is a mixed methods study completed in an applied, clinical setting using retrospective data. Quantitative and qualitative parts of the study were conducted sequentially. Quantitative data were gathered when parents answered a questionnaire and granted permission to access clinical data at CCR. A sub-sample of parents completed a qualitative interview. Mixed-method research designs are now widely accepted in social sciences (Creswell, 2009; Haines, 2011; Hanson, Creswell, Clark, Petska, & Creswell, 2005). “Using a mixed methods approach would make it possible for researchers to listen to parents and integrate their voices in quantitative research” (Watson et al., 2011, p.60).

Participants

The pool of participants for this study were parents or caregivers of children who had gone through the diagnostic process to determine the presence (or not) of an ASD who resided within the Sudbury/Manitoulin catchment area for CCR at the time of recruitment. Eligibility requirements included parents having accessed any autism related service at CCR for either diagnostic services, for the purpose of determining eligibility for intensive intervention, or for behavioural support whether their child had been diagnosed or not. CCR is the only provider of services for this population in this demographic region. Parents/caregivers were excluded if they had not been with the child at the time of the diagnosis or in the event a child was in foster care, if the child had been in the same foster family for less than three years at the time of the diagnosis. The preceding information was obtained by chart review.

A list of 536 potential participants was generated with the assistance of the Data Coordinator at CCR. All children who had not yet completed the diagnostic process were then

excluded from the list. Also, a file review was completed to remove anyone from the list who may have been placed there accidentally due to human error (i.e., if an employee had at one time opened an autism clinical or diagnostic service and then closed it again, indicating it had been opened accidentally.) A preliminary chart review of the remaining children resulted in a group of eight children being excluded because they had been in a new living environment for less than three years at the time of the diagnosis, which could have artificially reduced the wait times for this group. One child was excluded because he had been with his mother at the time of the diagnosis, but was currently living in a group home. There was no information regarding his mother's address.

Of the 416 research packages mailed out, 39 were mailed out to two different addresses for the same child (often because the parents were separated but both parents addresses were on file), amounting to an initial mail out to 377 unique clients. Additionally, 22 of those unique clients' questionnaires were returned to sender by the post office, amounting to a total sample of 355. Thirty-four questionnaires were returned and completed. If the "return to sender" questionnaires are accounted for as failure to contact versus refusal, the overall response rate is approximately 10.4 percent.

Of the 34 questionnaires that were returned, 30 parents/caregivers consented to joining their child's specific information (i.e., IQ, adaptive abilities, severity) to the information they provided. One parent did not sign the consent form for the survey and her responses were at times not plausible. For example, she reported herself as male, mother, 14 years of age with a university education, her son having received a diagnosis through the ADT at 13 years of age following 11 years of testing, although her first concerns weren't brought forward until her son was 4 years old. That participant was removed from the study. One other participant had never

completed the assessment process due to frequent moves. The final analysis therefore included 32 participants. Additionally, 12 of those 32 participants completed the qualitative interview.

Description of the sample. A description of the participants who completed the questionnaire was obtained through frequency distributions and measures of central tendency. All parents and children had gone through at least one full diagnostic process between 1999 and 2012. Most participants had been diagnosed by a single professional (see Table 1). File information was used to verify group. Forty percent of parents who completed the questionnaire and actually completed the diagnostic process through the ADT reported having been diagnosed by a single professional, suggesting that although the intent of the ADT is to offer a multidisciplinary service, this is not immediately evident to parents involved in the process. Four children in the sample had not been diagnosed with an ASD following the assessment procedures. Many of children were diagnosed with a milder form of ASD (46.9 %). None of them had received this diagnosis through the ADT. This distribution is not surprising, given that the tools used at the ADT allow for more specificity in diagnosis.

Table 1
Diagnosis by Group

Group	Diagnosis					Total
	severe autism	moderate autism	mild autism	ASD/PDD ASP	No ASD diagnosis	
Single Practitioner	12.5% (4)	9.4% (3)	6.3% (2)	46.9% (15)	9.4% (3)	84.4% (27)
ADT	6.3% (2)	3.1% (1)	3.1% (1)	0% (0)	3.1% (1)	15.6% (5)
Total	18.8% (6)	12.5% (4)	9.4% (3)	46.9% (15)	12.5% (4)	100% (32)

Note: ASD = Autism Spectrum Disorder, PDD = Pervasive Developmental Disorder, ASP = Asperger's Disorder. (n) = number of participants

As expected, the majority of children were male (78 %). On average, all testing for these children had been completed by the time the child was 6.7 years old, although this statistic was quite variable, with a standard deviation of 4 years. Some children were not referred for an assessment of intellectual ability and adaptive functioning at the time they were diagnosed with an ASD. Wait time variables for these children were therefore limited to wait between initial concern and initial diagnosis.

Child specific information was also highly variable (see Table 2). A Full Scale intelligence quotient (FSIQ) was available for 23 out of 32 participants, with an average IQ of 72 and a standard deviation of 21. Six children had an IQ score in the range of moderate impairment, ten children in the range of mild impairment, and seven children in the average range. Severity ratings based on the Childhood Autism Rating Scale (CARS; Schopler, Reichler, & Renner, 1986) were available for 13 of the 32 participants. The average CARS score was 36.6 (SD = 5.2). Of the participants for whom we were able to retrieve information regarding IBI eligibility (59%), half had qualified for Intensive Behavioural Intervention (IBI) and were either receiving IBI or waiting for that service while the other half were not deemed severe enough to qualify for this intensive service. Non-respondents could not be compared to respondents since their information remained confidential in the absence of a signed consent form.

Table 3 reports parent demographic information. The average age of the parent completing the surveys was 39 years (SD = 8), with most parents currently in their 30s and 40s (75%). The average age of parents at the time of diagnosis was 35 (SD = 7). An average of 4 years (SD = 3) had elapsed since their child had been diagnosed. All participants reported receiving services in the language of their choice. The majority of respondents were English speaking Caucasian mothers and they tended to be married (78%), with a college or university

Table 2
Child Clinical Data

Variable	Percentage of participants	(n)
Diagnostic Group		
Single Practitioner	84.4%	(27)
ADT	15.6%	(5)
Diagnosis		
Autism – severe	18.8%	(6)
Autism – Moderate	12.5%	(4)
Autism – Mild	9.4%	(3)
PDD-NOS/Asperger's	46.9%	(15)
Not on spectrum	12.5 %	(4)
Measured Intelligence		
Moderate Impairment	18.8%	(6)
Mild Impairment	31.3%	(10)
Average Functioning	21.9%	(7)
Missing	28%	(9)
Gender		
Male	78.1%	(25)
Female	21.9%	(7)
Involvement in IBI		
Qualifies for IBI	31.3%	(10)
Does not qualify for IBI	28.1%	(9)
Missing	40.6%	(13)

Note: ADT = Autism Diagnostic Team; (n) = number of participants;
PDD-NOS = Pervasive Developmental Disorder Not Otherwise Specified;
IBI = Intensive Behavioural Intervention

education (59.4% of mothers). No differences were noted between participants who completed the questionnaire and those who additionally completed a qualitative interview.

Measures

The following types of measures were used to gather data on the participants and their children: 1) Demographic measures (parent and child specific); 2) Wait Times measures; 3) Satisfaction measures; 4) Confidence in the diagnosis, and 5) Qualitative interview about the

TABLE 3
Demographic Information – Parent/guardian.

Variable	Percentage of participants	(n)
Gender		
Female	97%	(31)
Male	3%	(1)
Relationship to child		
Mother	94%	(30)
Grandmother/guardian	3%	(1)
Father	3%	(1)
Marital Status		
Married/Common law	78%	(25)
Single	22%	(7)
Language		
English	72%	(23)
French or bilingual (French and English)	28%	(9)
Race		
Caucasian	87.5%	28
Aboriginal	3.4%	1
Missing	9%	3
Income		
Under 20 000	9.4%	3
20 000 to 39 999	3.1%	1
40 000 to 59 999	21.9%	7
60 000 to 79 999	18.8%	6
80 000 to 99 999	9.4%	3
Over 100 000	31.3%	10
Missing	6.3%	2

experience. Parents were invited to complete a brief survey primarily for the purpose of determining who assessed their child, how long it took and the comprehensiveness of the assessment, how confident parents were in the diagnosis, how satisfied they were with the diagnostic process, and what they might suggest to improve the process for others. As well,

parents were asked to answer questions pertaining to their demographic information (age, gender, current age of child, socio-economic information). A copy of the questionnaire can be found in Appendix A). Child-specific data such as Full Scale IQ, Broad adaptive skills, and severity of autism were taken from psychological assessments completed at or near the time of diagnosis which were on file at CCR. All information was collected retrospectively.

Demographic measures. Demographic information regarding the parents/caregivers was requested as part of the quantitative part of the study. Participants were asked about their current age, educational attainment, family income, marital status, ethnicity, and the amount of time that had elapsed since the diagnosis. If parental consent was received, time since diagnosis was also verified through the clinical file review.

Wait times. Wait times were examined. The family's wait times were calculated based on information they provided and the clinical file information. Two different wait times were calculated. Wait times were defined as (a) the length of time between the date when the concern was first presented to a professional and the diagnosis, and (b) the length of time between the date when the concern was first presented to a professional and when a specific diagnosis was provided and all of the accompanying testing was completed. Often, this was when the child had completed a longer battery of tests including the Childhood Autism Rating Scale (CARS) or other autism scales, cognitive testing, adaptive skills testing, and possibly an Autism Diagnostic Observation Schedule (ADOS). Parents received a diagnosis from either their pediatrician, a psychologist in private practice, Developmental Clinical Services (prior to 2007), Autism Clinical Services (2007 to present), or the ADT (2010 to present). The ADT was the only diagnostic provider that was considered a multidisciplinary team. All other diagnostic providers were considered single-practitioners. When the parents allowed access to the child specific

information housed in a clinical file at CCR, the information they provided on the questionnaire was verified and corrected as needed. In the event of a discrepancy, the file information was retained.

Satisfaction. The family's experience and satisfaction with the diagnostic process was examined. Parental satisfaction was marked on a Likert-type scale ranging from 1 (not satisfied) to 5 (extremely satisfied). Questions were divided into two sub-scales: satisfaction prior to and during the assessment (questions 9.1 – 9.5), and satisfaction at the time the results were shared with the family (questions 9.6 – 9.9). In addition, all questions were included in a total satisfaction scale (see Appendix A). Sub-scale and total scores were calculated by adding the individual scores for each question in that sub-scale and dividing by the number of questions. One question regarding the confidence parents had in the diagnosis was also presented (Question 7). The scale questions were based on results of the Osborne and Reed (2008) study about what parents reported could have been improved or offered during the diagnostic process to make it easier.

Child Clinical Data. Children's clinical data was obtained via file review when consent was obtained (see Appendix B) and when the file was readily available to the research assistants. Information collected included 1) severity of diagnosis, and when consent was given, 2) cognitive ability and 3) adaptive skills. In the event the child had received multiple assessments, the initial assessment completed at the time of diagnosis or closest in time to diagnosis was used. All intelligence tests scores found in the clinical data used tests with a mean of 100 and a standard deviation of 15. The CARS was often found as a measure of severity. The CARS manual states that the purpose of this tool is to “identify children with autism and to distinguish them from developmentally handicapped children without autism” (Schopler et al., 1986, p. 1).

Fifteen items are scored on a seven point rating scale ranging from normal to severely abnormal based on parental report and observation in multiple settings. The possible range of scores is from 15 to 60, with a cutoff of 30 or higher said to be consistent with the likelihood of autism. Scores between 30 and 36 are considered mild to moderate, while scores of 37 or higher are considered severe.

Qualitative Component. This study was inspired by the phenomenological approach but was in fact a basic qualitative study (Merriam, 2002). The phenomenological approach “describes the meaning for several individuals of their lived experience of a concept or a phenomenon” (Creswell, 2007, p.57). Twelve participants engaged in an interview following Moustakas’ methodology (Creswell, 2007) with questions modeled after the Beatson and Prelock (2002) study. Participants were asked three broad questions relating to their experience of the process and contexts or situations that influenced or affected their experience along with one question regarding how to improve the process (Beatson & Prelock, 2002; Creswell, 2007). The questions were

1. You and your child went through several steps in the process of obtaining a diagnosis. Can you tell me what that was like for you?
2. Was there anything that you found particularly helpful?
3. Was there anything that you found particularly difficult?
4. Do you have any recommendations for improving the diagnostic process?

An open-ended technique was used in order to help parents remain on-topic regarding their experience of the diagnostic process while not making assumptions about the experience by providing leading questions. A short interview also respects the fact that these parents are usually faced with high demands in their daily lives and lengthy interviews would be overly

demanding of them (Beatson & Prelock, 2002). Interviews were all conducted at the family's home. They lasted twenty minutes to one hundred minutes. Two hundred and seven codes were assigned to these interview transcripts based on the coding method described in the procedures section.

Procedures

Potential participants were mailed a research package including an introductory letter (Appendix C), consent form (Appendix B), questionnaire (Appendix A), and return envelopes. Parents were invited to complete a brief survey. On the consent form, families could consent to completing the questionnaire and returning it in the pre-stamped envelope, but they could also consent to a file review for the collection of child-specific data and participation in an interview regarding their experience going through the diagnostic process with their child. By providing their contact information on that section of the consent form, parents or caregivers could opt into the interview.

If the parent/caregiver consented to a file review, the child's name and date of birth were provided. Child-specific information accessed included IQ, adaptive skills, and severity of autism at/near the time of diagnosis, if these were available. Diagnosis and diagnosis date were also confirmed by verifying file information.

Once the questionnaire was returned to the researcher, a research assistant provided the participant with an identification number to protect the family's privacy as much as possible. Data were entered into SPSS. The research assistant completed a file review for children whose parents consented to this level of participation and added that information to the SPSS file. The file review was of interest because there was some concern that child specific characteristics may

be influencing the parental experience, and for that reason, child specific variables should be tracked and monitored.

Research assistants also took note of which parents/caregivers provided consent to participate in the interview, and a list of potential interview participants was generated through this process. A research assistant familiar with conducting qualitative research then contacted families and arranged for interviews to take place in the family's home or at the university. The interviews were audio-taped and transcribed. Names were removed prior to sharing the transcriptions with the principal researcher.

Audio-recordings of the interviews were transcribed and the content was analyzed following a content analysis methodology. The following steps were undertaken:

- 1) The research assistant and principal researcher independently read and re-read the first few transcripts to look for patterns.
- 2) An initial coding scheme was developed and consisted of the following:
 - a. Code 1: Timing in relation to diagnosis
 - i. B = Before the diagnostic process started
 - ii. D = During the diagnostic process
 - iii. A = After the diagnosis
 - b. Code 2: Main focus of the comment
 - i. L = Professional
 - ii. S = Experience of the process
 - iii. T = Parental feelings
 - iv. M = Miscellaneous

- 3) Both the principal researcher and research assistant coded the first interview using an ID number, followed by the timing code and the main focus code. Codes were then made more explicit, as follows:
- a. Code 1: Timing in relation to diagnosis
 - i. B = Before the process was initiated
 - ii. D = Following initiation and during all assessments, including feedback meetings
 - iii. A = Following the feedback meeting
 - b. Code 2: Main focus of the comment
 - i. L = Comments about the professional
 - ii. S = Comments about the process
 - iii. T = Comments about parental emotions, needs, strengths, reactions, including feelings towards professionals.
- 4) Key sentences or words in the transcription were highlighted and notes were made regarding the context of the central comment. For example, the words “*so that was too much to take*” were coded as occurring during the diagnostic process (D), and relative to the parent’s (T) emotional state by both researchers. Additionally, the research assistant recorded the following comment: “Being present for the diagnostic process emotionally difficult for parents”, while the principal researcher recorded this comment: “emotionally difficult assessment set up”. The codes were the same and the comments were deemed the same, as they centered on the appointments themselves as being a source of discomfort for the parent.

- 5) In the event there was a disagreement regarding the code and its meaning, the principal researcher reflected on the merits of each researcher's analysis and chose the most appropriate code, or discussed the disagreement with the research assistant until a consensus was obtained.
- 6) Once all of the codes were finalized, they were sorted by Code 2 (the main focus of the code as either the professional, the process, or the parent). Two hundred and seven codes were assigned across the 12 interviews.
- 7) Once captured, similar comments and contexts were grouped together to synthesize the experiences reported, often based on the adjectives or adverbs parents used to describe their experience. An audit trail was used as comments were moved.
- 8) Themes were searched for until enough themes emerged to include everything that had been shared, so there was not a lot of omitted material. A theme was used to represent a large number of statements made by participants. Twenty-four themes were initially noted.
- 9) Themes were then streamlined to ten themes while maintaining the chronology of the assessment process (i.e., prior to, during, and after the diagnostic assessment.)

Ethical Considerations

This study received approval from the ethics review board at Laurentian University and subsequently the Research Advisory Committee at CCR (see Appendix D). In preparing this research project, the ethical considerations of informed consent, right to privacy/confidentiality, and general caring were taken into consideration. Informed consent was signed prior to recording of the questionnaire data. Parents were given a clear explanation of the nature of the research project and they were advised that they could withdraw at any time. They were also

informed that refusal or failure to participate in this study would not be held against them in any way. All information collected remained confidential and names were severed from the data immediately once it was received, and replaced by an identification number.

Participants had choice of time and location for their interviews. During the interview, participants' feelings were reflected back to them in an effort to ensure responsible caring (Arkowitz & Miller, 2008). Audio-recordings of the interviews were transcribed, with all identifying information removed, and then deleted.

Use of an Assistant. The Research Advisory Committee at CCR requested that the principal researcher distance herself from both the names on the questionnaires and from the interviews, because of her involvement in numerous assessments since 2007. Therefore, in an effort to minimize discomfort and encourage openness, research assistants were responsible for storing the names and addresses of potential participants, and severing the data from the names of completed questionnaires, once they were returned. The research assistants were not employees of CCR, and they were recruited externally. A research assistant with experience in qualitative interviews was used to complete the one-to-one interviews.

Chapter III: Results

The purpose of this study was to explore the relationship that parental satisfaction has with the type of diagnostic service received by families when receiving an assessment for ASD. The satisfaction of parents who had their child assessed by a single practitioner was compared to that of parents who had their child assessed by a team of practitioners working together. Additionally, given that wait times were anticipated to have been reduced since the inception of the ADT, the relationship between wait times and satisfaction was also explored. Parental confidence in the diagnosis was not found to be related to any other variable and therefore will not be discussed further. The results are presented by looking first at wait times, then satisfaction. The results of the qualitative component, reflecting mainly the experience of receiving a diagnosis from a single practitioner, is discussed last.

Wait Times

Are wait times shorter for children who were assessed through the ADT compared to those who did not receive a diagnosis by a multidisciplinary team?

The average for “Wait Time to Diagnosis” for the entire sample was 3.51 years ($SD = 3.27$). The second variable, “Wait Time to Specificity”, is the wait between the first concern and when a specific diagnosis was provided, or when all of the testing that was requested was completed. The average for “Wait Time to Specificity” for the entire sample was 4.03 years ($SD = 3.95$). Although the wait for a diagnosis can be quite long, the variability indicates that some children receive their diagnosis much more quickly than others, with wait times ranging from zero to almost 16.92 years. Both distributions were positively skewed (Waittime to Diagnosis Skewness index = 5.34; Waittime to Specificity Skewness index = 4.27), therefore non-

parametric statistics were used to examine group differences because such statistics do not assume a normal distribution. No significant differences were found between group medians or means. However, the standard deviation for the single professional group was elevated compared to the standard deviation for the ADT (Homogeneity of variance: Wait time to Diagnosis $F=4.20, p=0.05$; Wait time to specificity $F=5.36, p=0.03$). Although children do not wait longer in one group or another, their experience in the ADT is much more uniform (see Table 4). The most extreme cases come from the single professional group. No differences were noted when controlling for the number of mild ASD diagnoses provided by single practitioners.

Table 4
Standard Deviations by Group

Group	Wait Time to Diagnosis SD	Wait Time to Specificity SD
ADT	0.69 years	0.69 years
Single professional	3.75 years	4.18 years

Note: SD = Standard Deviation

Satisfaction

Do parents who go through the diagnostic process with the ADT report higher levels of satisfaction overall than parents who go through the diagnostic process with a single professional?

The average satisfaction scores for the entire sample were: *satisfaction prior/during assessment* = 2.86; *satisfaction with diagnostic sharing* = 3.25; *overall satisfaction* = 3.02.

Satisfaction prior to and during the assessment fell between the “somewhat satisfied” and “satisfied” ranges. Satisfaction with the diagnostic sharing experience fell between the “satisfied” and “very satisfied” ranges. Overall satisfaction fell in the “satisfied” range. None of the scales were skewed. The assumption of equality of variances was met. No significant differences were noted between groups. Parent level of satisfaction was not increased by their

participation in a multidisciplinary diagnostic team versus a diagnostic process completed by a single practitioner (t-test, $t_{30} = -1.11$, $p = 0.28$). When looking only at those children diagnosed with a severe form of autism spectrum disorder to control for the over-representation of diagnoses of mild ASD provided by the single practitioner group, no significant differences were noted (t-test, $t_{11} = -1.22$, $p = 0.25$). There was no relationship between satisfaction and child's age at the time of diagnosis (Pearson Correlation, $r_{32} = 0.02$, $p = 0.91$) and additionally no relationship was noted between satisfaction and the amount of time that had elapsed since the diagnosis had been provided. There was no relationship between overall satisfaction and wait time to diagnosis (Spearman's rho, $\rho_{30} = -.24$, $p = .20$) or wait time to specificity ($\rho_{29} = -.22$, $p = .24$).

Points of Interest for Practitioners

The following section provides additional findings that may be of interest to practitioners. First, the comprehensiveness of the assessment is examined, followed by differences based on demographic variables. Finally, differences based on child specific variables are reported.

Comprehensiveness of the assessment. A dummy variable was created to help capture the comprehensiveness of assessments that children received. Children who received their diagnosis prior to completing cognitive and adaptive testing received a code of 0, while those who received their diagnosis following the completion of cognitive and adaptive testing received a code of 1. In examining the dataset, we were able to determine that children did not receive a more or less comprehensive assessment based on family income or parental education level. Those children who were later deemed to have a mild cognitive impairment were more likely to receive their ASD diagnosis prior to having a full assessment of their intellectual and adaptive functioning, whereas children with an average IQ tended to receive their intelligence testing first, followed by an ASD assessment and diagnosis (Kruskal-Wallis, $\chi^2_2 = 7.25$, $p = 0.03$; see Table 5).

Non parametric tests confirmed that the ADT group was more likely to complete a comprehensive assessment prior to the diagnostic meeting (Kruskal-Wallis, $\chi^2_1 = 5.07$, $p = 0.02$), whereas children whose assessments were completed by a single practitioner were less likely to have completed a comprehensive assessment prior to diagnosis (see Table 6).

Table 5

*Comprehensiveness of initial diagnosis by category of cognitive ability**

Group	Comprehensiveness of Initial Diagnosis		
	(n)	Mean Rank	Mean Comprehensiveness (SD)
Moderate cognitive impairment	6	13.17	.33 (.52)
Mild cognitive impairment	10	14.70	.20 (.42)
Average cognitive ability	7	7.14	.86 (.38)
Total	23		

Note: (n) = number of participants; SD= Standard Deviation

* $p < 0.05$

Table 6

*Comprehensiveness of initial diagnosis by type of practitioner**

Type of practitioner	Comprehensiveness of Initial Diagnosis		
	N	Mean Rank	Mean Comprehensiveness (SD)
Single professional	27	17.89	.44 (.51)
Autism Diagnostic Team	5	9.00	1.00 (0.0)
Total	32		

Note: N = number of participants; SD=Standard Deviation

* $p < 0.05$

Parents were not more or less satisfied in relation to the comprehensiveness of the information available prior to the diagnosis. Parents did not report greater confidence in the process when they had received a comprehensive assessment prior to the diagnosis. However, having this information does facilitate access to appropriate services. This finding should

therefore not be overlooked as a full assessment of a child's strengths and weaknesses is considered best practice at the time of diagnosis (Nachshen et al., 2008).

Differences based on parental demographic variables. Differences in wait times and satisfaction were at times found based on parental demographic variables. Specifically, differences were noted on parental marital status, income, and language variables. Results are presented below.

Marital status and income. Overall parental satisfaction was higher for single parents (t-test, $t_{30} = -2.98, p = .01$). Prior to or during the assessment process, single parents reported higher levels of satisfaction with the process than married parents. Married participants tended to respond between the "somewhat satisfied" and "satisfied" categories with a mean of 2.72 ($SD = 1.14$) whereas single participants tended to respond between the "satisfied" and "very satisfied" categories, with a mean of 3.57 ($SD = 1.40$). Not surprisingly, there was a significant relationship between marital status and household income, with married couples reporting higher levels of income (Pearson Chi-Square, $\chi^2_5 = 18.28, p = 0.00$). There were no differences among income groups on the variables of Wait time to diagnosis (Kruskal-Wallis, $\chi^2_5 = 8.03, p = 0.15$) or Wait time to specificity (Kruskal-Wallis, $\chi^2_5 = 9.87, p = 0.08$). Families with higher incomes did not benefit from shorter wait times. Single and married parents were distributed randomly among diagnostic groups (Pearson Chi-Square, $\chi^2_1 = 1.14, p = 0.29$).

Language. There were no differences among language groups on overall satisfaction (t-test, $t_{30} = .42, p = .68$). Parents who self-reported being French (monolingual and bilingual) were reporting satisfaction levels similar to English parents. No differences among language groups were noted on any measures. Single practitioners and the ADT did not differ in the proportion of francophone children they assessed.

Differences based on child specific and clinical data. While exploring the child specific variables, some differences were noted. Gender differences emerged, as well as wait time differences between different types of diagnoses. These differences are discussed below.

Gender. Girls waited longer than boys to obtain their initial diagnosis of ASD (Kruskal-Wallis $\chi^2_1 = 5.52, p=0.02$) and to have their full assessments completed (Kruskal-Wallis $\chi^2_1 = 6.76, p=0.01$; see Table 7). However, there was no impact of gender on satisfaction. Parents also reported that professionals were spending more time with girls during the diagnostic process (Kruskal Wallis, $\chi^2_1 = 4.80, p= 0.03$), which is understandable given the lower prevalence rate for female children (Fombonne, 2009). Because ASD is less common in females, using this diagnostic label may require greater consideration and support.

Table 7
Wait Time Ranks by Gender

Variable	Child's gender	N	Mean Rank	Mean Wait Time in yrs (SD)
Wait to diagnosis *	Female	7	23.86	5.38(3.03)
	Male	25	14.44	2.68(3.45)
	Total	32		
Wait to specificity *	Female	7	23.86	7.20(4.05)
	Male	24	13.71	3.10(3.48)
	Total	31		

Note: N = number of children; SD=Standard Deviation; yrs= years

* $p<0.05$

Severity of Diagnosis. There is a significant difference in wait times between groups of children with different diagnoses (Kruskal-Wallis, $\chi^2_4 = 13.58, p=0.01$). Means for all groups helped identify that children diagnosed with a mild ASD wait the longest. Children at the mild end of the autism spectrum tend to wait longer than children who are more obviously diagnosable

(severe and moderate autism and non-ASD; see Table 8). There is no difference in overall parental satisfaction between groups of children with different diagnoses.

Table 8
*Mean Rank for Wait time to specificity by diagnosis***

Diagnosis	(n)	Mean Rank	Mean Wait Time in years (SD)
severe autistic	6	9.75	1.61 (0.83)
moderate autistic	3	12.25	1.19 (0.30)
mild autistic	3	16.33	5.72 (7.18)
ASD/PDDNOS/ASP	15	21.40	5.86 (3.93)
Non-spectrum/No diagnosis	4	12.63	1.63 (1.17)
Total	31		

Note: (n) = Number of children; SD = Standard Deviation; ASD = Autism Spectrum Disorder; PDDNOS = Pervasive Developmental Disorder Not Otherwise Specified; ASP = Asperger's
**p<0.01

A similar finding was noted regarding IBI eligibility. Children who did not qualify for IBI waited significantly longer than children who did qualify for IBI to receive their initial diagnosis (Kruskal-Wallis, $\chi^2_1 = 9.67, p=0.00$) and to have all related assessments completed (Kruskal-Wallis, $\chi^2_1 = 7.27, p=0.01$; see Table 9).

Table 9
Mean Rank for Wait time by IBI eligibility

	IBI Eligibility	(n)	Mean Rank	Mean Wait Time in yrs (SD)
Wait time to diagnosis**	Does not qualify for IBI	9	14.22	3.84(2.39)
	Qualifies for IBI	10	6.20	1.01(0.52)
	Total	19		
Wait time to specificity**	Does not qualify for IBI	9	13.67	5.69(3.93)
	Qualifies for IBI	10	6.70	1.66(0.89)
	Total	19		

Note: IBI = Intensive Behavioural Intervention, (n) = Number of children, SD = Standard Deviation, yrs = years
**p<0.01

Because children who qualify for IBI tend to fall at the more severe end of the spectrum, this finding is consistent with the above mentioned findings. As well, it is consistent with the pediatricians' preferred practice of prioritizing the more severe cases to facilitate appropriate early intervention. Nonetheless, IBI eligibility was not related to satisfaction.

Summary of Quantitative Findings

Results show that children and parents waited between three and four years to received a diagnosis in the Sudbury region, with girls and children with milder forms of ASD waiting the longest, and children with more severe forms of ASD who qualified for IBI waiting the least amount of time. There were no significant differences between the ADT and single professional groups on the variables of wait time and satisfaction. However, children receiving a diagnosis through the ADT all had very similar experiences in terms of the wait time, the comprehensiveness of the assessment, and the timing of the cognitive and adaptive assessment; no family waited an inordinate amount of time to have their assessment completed.

Overall, the groups reported being satisfied, with no group differences in reports of satisfaction. Although the single professional group was less likely to receive a comprehensive cognitive and adaptive assessment prior to diagnosis, parental level of satisfaction was not related to the timing of this portion of the assessment. Parental satisfaction was highest for single, lower income parents. There was no difference in satisfaction between English and Francophone families.

What is the Diagnostic Experience?

The purpose of the qualitative interview was to better understand the experience of going through the diagnostic process, but also to gather specific information regarding the experience of receiving a diagnosis through a multidisciplinary team. Of the 12 interview participants, two

had children who did not receive a diagnosis of ASD and these families reported extremely negative views of the process, professionals, and related reactions and feelings. In order to focus on the experience of receiving a diagnosis of ASD, these families will be discussed separately, leaving ten families for the main analysis. Although three of the 12 participants had involvement with the ADT at some point in their diagnostic experience, only one family remained with the ADT until a diagnosis was provided. One of the three participants left the ADT wait list to have their assessment completed in private practice. A second family did not receive a diagnosis following their ADT experience and therefore was not included in the main analysis of the qualitative interviews. This left one participant to provide a better understanding of the experience of completing an assessment through the ADT (see Table 10).

Table 10
Information on Participants for Qualitative Interview

ID#	Type of Practitioner	Diagnosis	Gender	IQ
1	ADT	Severe autism	Male	Mod delay
11	Single Practitioner	Moderate autism	Male	Mild delay
12	Single Practitioner	Moderate autism	Male	Mild delay
16	Single Practitioner	ASD	Male	Mod delay
17	Single Practitioner	ASD	Female	Mild delay
20	Single Practitioner	Moderate autism	Male	Unknown
23	Single Practitioner	Severe autism	Male	Mild delay
25	Single Practitioner	Severe autism	Male	Mod delay
21	Single Practitioner	ASD	Female	Mild delay
30	Single Practitioner who first waited for the ADT	ASD	Male	Average
Excluded from main qualitative analysis:				
7	ADT	Not ASD	Male	Average
26	Single Practitioner	Not ASD	Male	Unknown

Note: ADT = Autism Diagnostic Team; IQ = Intellectual Quotient; Mod delay = Moderate delay

With such small participation in the qualitative interviews by families who completed the ADT process, the specific experience of receiving a diagnosis through this process could not be explored. This portion of the study will therefore focus more on adding to the body of literature on a parent's experience going through the diagnostic process with their child when ASD is the main diagnosis being considered. Qualitative data mainly reflects the experience of receiving a diagnosis from a single practitioner. The two families who did not receive a diagnosis of ASD will be discussed separately. As well, the group of three who were involved with the ADT in some capacity will be discussed as their stories provide a glimpse at the experience of participating in the ADT, although the limited data does not justify an overall generalization.

Overview of themes. In their interviews, parents consistently commented on the diagnostic process, the professionals involved in that process, the feelings they experienced as a result of both, and the manner in which they coped. These consistent patterns, which in a sense described the chronology of events, were retained as domains. Similarly grouped statements carried different emotional tags. Adjectives and adverbs were often used to help determine whether the parent was reporting the event as a negative, positive, or neutral contributor to the experience. Examples of negative comments included the words "*grieving*," "*overwhelming*," "*intimidating*," "*guilt*," "*worry*," "*burned out*," "*terrible*," "*hard*," and "*condescending*". Examples of positive comments included "*safe*," "*empathetic*," "*fantastic*," "*patient*," "*nice*," and "*helpful*". Mixed emotions were reported when parents talked about both positive and negative emotions in regards to the same theme, whereas a parent's reaction was deemed neutral when they mentioned a theme without referring to any related emotion, either positive or negative. When a theme is reported as positive, there was a preponderance of positive comments

(i.e., over 66%), and likewise when a theme is reported as negative, there was a preponderance of negative comments.

Parents reported a preponderance of negative emotions. However, no parent was either completely negative or positive in their report, suggesting their experience was filled with ups and downs. The following themes emerged and they were categorized within four domains. Theme names are listed below, by domain. Theme names are followed by a quote from a participant to illustrate the theme. Given that chronology was maintained, some overlap is noted, as similar themes may have emerged in different contexts or domains. Please note that throughout the document, participant quotes are italicized and placed in quotation marks. A table summarizing the information can be found in Appendix E.

In regards to the process and associated feelings, three themes emerged which mainly captured the experience prior to and at the onset of the assessment:

- 1) Difficulty activating the assessment process: *"The first one that brings that up"*
- 2) Concerns regarding the wait: *"A lengthy process"*
- 3) Appointment demands: *"We went to six appointments"*

In regards to the domain of reactions to professionals and associated feelings, two themes emerged which mainly captured the experience during the assessment itself, including the sharing of diagnostic information:

- 4) Respectful communication (overarching theme)
 - a. How well professionals listened to parents: *"Take the time to listen"*
 - b. Share your knowledge, but be kind: *"How it's going to turn out"*
- 5) Professional expertise: *"Autism specialists"*

In regards to the domain of feelings relating to the diagnostic experience, two themes emerged which spanned the chronology of the entire process:

- 6) Deep distress: *“Devastating”*
- 7) Perceived abandonment: *“Kind of got left hanging”*

Finally, in relation to the coping domain, three themes emerged:

- 8) Emerging agency: *“Case management”*
- 9) Feeling gratitude: *“I’m grateful”*
- 10) Acceptance and support: *“A big part of the journey is acceptance”*

Each theme is summarized and then illustrated with examples below.

The process and associated feelings. Regarding the process, parents presented information in a negative, positive, or neutral view regarding how they came to be engaged in the assessment process, the wait times for assessments, the comprehensiveness of the assessment, as well as the amount of information provided to them through the process. Most comments regarding the process and associated feelings related to the time prior to and at the onset of the assessment. Parents reported difficulty activating the process as well as concerns regarding the wait and the appointments.

Difficulty activating the assessment process: “The first one that brings that up.” There are systems and processes in place to facilitate the diagnosis of children with autism spectrum disorders. The average child’s age at which participants in this study first reported their concerns to a professional was three, with a range between 6 months and 11 years. All participants brought this theme forward during their interview; however, four out of ten families reported this theme in a neutral fashion. One family who referred to themselves as *“lucky, at the right place, at the right time”* reported gratitude about the ease with which they were able to initiate the

process by mentioning concerns to the family physician who quickly referred for an assessment. However, fifty percent of families interviewed reported negative comments regarding the initiation of this process. The difficulties encountered by these families in activating the assessment process are discussed next.

One participant had difficulty convincing their family doctor to refer them for further testing. As this parent stated: *“I wanted to go further but my doctor kept saying ‘oh no’. He didn’t think there was anything wrong with my daughter.”* That no one was listening to them resulted in feelings of needing to fight with the “system”, and this seemed to set the tone for their on-going relationship with service providers. *“You have to be persistent. You can’t just sit back and wait ‘til they call you. You need to call and you need to talk to people and tell them.”*

A few parents mentioned that certain professionals along the way had observed symptoms of autism in their child but did not follow through with a referral for an assessment. As one parents stated: *“His first speech pathologist that saw him at 2 1/2 years old noticed that he was flapping his hand and said: ‘you need to get him to stop that or people are going to think he has autism’. That was a red light right there. So we went on for two more years before another speech language pathologist said we need to get him tested.”* This child was later diagnosed with moderate autism.

Finally, two parents were shocked at being informed about the possibility of an ASD, not having had any concerns relative to ASD prior to it having been suggested. Those parents were particularly offended and upset. One of the two participants stated: *“So in the initial, in the first few months going through that process we were really upset, and basically you’re always mad at the first one that even brings that up, so we’re not too happy with this doctor at that time.”* The other was very off-put by the perceived lack of professionalism at the daycare that initially

suggested the possibility of autism and that parent pushed off the assessment for another three years following the first suggestion. That participant suggested that: *“unless a parent is ready to accept that information, to be quite honest there is nothing that you can do as a person working in the continuum to change that.”* Both of these parents’ children were eventually diagnosed with severe autism.

Concerns regarding the wait: “Lengthy process.” Once the referral had been initiated, all parents were faced with having to wait for the service to be delivered. All parents talked about the amount of time they were required to wait. Also, multiple consecutive wait times were reported by six out of 12 families, including one family who had at one point been on the ADT waitlist and another family who received an assessment through the ADT, but no diagnosis.

One parent who had received their diagnosis through the ADT reported her wait time in a very neutral manner. The entire psychological assessment was completed and a diagnosis was shared with the family within a year and a half of the initial concern, when the child was still a toddler. Similarly, the parents who had felt very lucky about their experience initiating the diagnostic process received a diagnosis in less than 9 months from the time they first presented their concerns to their family physician. These parents reported positive feelings about the wait time, saying: *“I can’t speak highly enough of how quickly it was diagnosed and how programs were made accessible.”* They received their diagnosis long before the ADT was in place.

Eighty percent of parents (8 out of 10) reported negative emotions regarding their wait time: all of them talked about frustration. One parent said *“There’s not enough doctors, not enough specialists in the city. Everything takes a long time. It’s frustrating trying to see pediatrician; you wait to see the pediatrician to get the proper diagnosis. That’s the most frustrating for the parent.”* Another stated: *“It’s a very lengthy, very frustrating process (...)*

having to be in the system and being lost in the system more than once.” Other negative words brought forward in relation to the wait time included “intimidating,” “awful,” “lengthy,” and “ridiculous.” As one parent commented: “I would say a sufficient wait time for a psychological assessment is maybe, you know, like four months. Okay, I understand, you know, there's other people too but not a whole year. A whole year is huge when your child has autism. And then you're another wait on top, like you have to wait that whole year, and then you get on the IBI waitlist and start your two-year wait after that. So then now we're into three years right. So it's just a whole waste of time. Just that whole (assessment) step seems like a waste.”

The perceived lack of information about what to expect during this time was mentioned by 50% of participants. For example, one parent stated: *“We were very confused. We weren't told that he was going to be on this waitlist for up to a year.”* The ADT participant was the only one who reported receiving a good picture about what to expect and related positive feelings on the issue: *“She explained the process that was going to be happening. She was very warm. She answered all my questions. She made me feel very secure and safe.”* Prior knowledge of “the system” was brought forward by 2 of the 10 families, and both families viewed this as a strong advantage for them in navigating the various agencies. Perceived lack of information is a theme that repeats itself later on in the diagnostic experience as well.

Finally, because wait times are so long, three parents reported dealing with either staffing changes or changes to the process itself, all referred to in a negative fashion: *“but then they changed again, like they are constantly changing the way they're doing things. Just pick something and stick to it, you know?”* Participants were not always sure who they needed to talk to for support or in order to get information.

Appointment Demands: “We went to six appointments.” Interestingly, eight out of ten participants talked about the number of appointments they needed to attend and the comprehensiveness of those appointments. The majority of those (5/8) presented this information in a neutral fashion (for example, “*he went to the center several times*”). The remainder of the parents had negative comments regarding the excessive demands of the psychological assessment (the severity assessment). A lengthy assessment process disrupted the routine. Two parents felt the physical environment of the testing situation was “*cramped*” and “*intimidating*.” Three parents had difficulty watching their children do poorly during standardized testing: “*And they are keeping score of your child. That was hard to take.*” Parents felt as if professionals were comparing their child to others and this was very difficult for them to accept. One parent also perceived the testing to be hard on their child’s self-esteem.

Reactions to professionals and associated feelings. Parents described how they had been treated by various professionals during and immediately following the assessment. Specifically, they discussed positive, negative or neutral views regarding how professionals communicated with them. This overarching theme of respectful communication was very prevalent, and two distinct themes were used to better capture the essence of the theme. Themes included the professionals’ ability to listen to parents and their ability to respectfully share their knowledge with the family. The expertise of professionals involved in their child’s diagnosis was also an important theme. Forty percent of participants reported generally positive diagnostician attributes, including the parent who had received a diagnosis through the ADT. An additional ten percent maintained a neutral impression of their main diagnostician. Twenty percent of participants reported both positive and negative qualities about their diagnostician while thirty percent had nothing but negative comments about them.

How well professionals listened to parents: “Take the time to listen.” Eighty percent of participants talked about their feelings regarding how well the professionals involved with their child listened to them. Half of those had very positive comments, including comments from the ADT group participant. For example, one parent who was worried about the possibility of a misdiagnosis of autism stated the professional involved *“reassured me that if I didn’t agree with the diagnosis that there were options for me, which I thought was very, very good.”* Another had concerns about a possible genetic cause of the ASD, and the child’s pediatrician investigated this possibility for her, thus leaving her with the feeling of having been listened to.

Two parents went a step further and felt that the professionals involved in the diagnostic process were not only listening to them, but also being empathetic in their interactions, further substantiating the desire to receive respectful communications. *“Everyone was very empathetic, and the child was given lots of different places to run and things to play with”.* The professional *“took my lead. It wasn’t as if (the professional) was you know, going to come in and tell me the way it was.”* The concept of empathic listening emerged in forty percent of participants, with two out of the ten participants feeling like the professionals lacked empathy: *“At times, it’s like ‘okay, here comes another whining parent’. It would be nice to have someone there that knows what you’re going through.”*

Of the four participants who reported not feeling heard, one parent had this to say: *“Believe the parent. I do spend most my time with her and (professionals) need to take into account what I know and what I see on an everyday basis (more) than what they see for six hours or less in school.”* Another parent who had seen multiple service providers and had waited a long time to access the assessment in question was *“shocked”* when her offer to provide copies of reports she had been collecting was turned down by the professional completing the

assessment: *“And you know, she didn't want any of that initially. I was really shocked, because some of the, you know the therapist reports and things like that clearly indicated some of the things that they wouldn't have seen (one-to-one).”*

Additionally, frustration regarding having to repeat oneself was noted by thirty percent of participants. One parent stated: *“You wanted one thing, you had to do one intake. You wanted something else, you had to do another intake.”* Another parent who was familiar with the intake process and the requirements for various services stated being overwhelmed that *“even though everything's on the computer, you're still going through repeating yourself again. You have to repeat yourself every time at the doctor, in the hospital when you're there with, with the doctors about the whole process.”* The disbelief at the lack of organization was noted when one parent stated: *“you know if I get asked one more time ‘how was the pregnancy and the birth’ like you know, I've told six different people that answer, if you, you're supposed to have it in your system, you know (laughing). Like it's just the same thing over and over and over again from different people.”*

Share your knowledge, but be kind: “How it's going to turn out.” Sharing of information was also reported as an important theme mentioned by eighty percent of participants, indicating that it wasn't only the diagnostician's level of expertise that was important, as will be discussed next, but the extent to which this expertise was shared with the parent or accessible to them during their encounters. As one parent stated: *“So, you know, I was able to, as a parent, get a lot of questions addressed. (The diagnostician) worked with children with autism for a very long time, so of course you totally milk that for what it's worth if you can get in front of (the professional), who was real and took the time to listen to what I had to say.”* Participants also

reported positive feelings regarding the sharing of what to expect following the diagnosis, for example, where they could receive service, and funding information.

Three of the ten participants made specific comments about the content of discussions regarding results of the psychological assessment. Two parents left the process with a clear understanding of their child's strengths, and those were mentioned during the interview suggesting this information was important to them. One parent whose child was diagnosed at two years of age stated: *"(a diagnosis) is not something you can just say 'this is what your son has and that's it'. There's so many different scoring and different things. For example, (child) is very very good with blocks; his gross motor skills, but he has no speech. So certain things he's developed at a seven-month level, other things he's only a three-month level."* For another parent, however, the sharing of poor prognostic information was unwelcome and associated with feelings of hopelessness: *"Professionals should not tell parents that your child may never speak again, or your child will never do this, or your child will never do that. They don't know that for sure. They can come up with the diagnosis, but like a death sentence, you don't know the dates, you don't know for sure how it's going to turn out."* Communicating about a child's strengths rather than their limitations was a style that parents noticed.

Another parent reported the diagnostician as *"abrupt"*, indicating that not only is the content of the meeting important to parents, but so is the warmth and compassion they receive from their diagnostician in the process of receiving this news. Both parents who reported receiving a diagnosis either over the phone or in a letter viewed this practice negatively: *"The (diagnostician) phoned my husband to give him the diagnosis. We felt it was inappropriate."*

Professional expertise: "Autism specialists." Eight out of ten participants mentioned the expertise of the professionals involved in their child's diagnostic process. Three of those

participants reported acknowledgement and gratitude regarding the level of knowledge possessed by their main diagnostician: *“The pediatrician was very helpful. We were fortunate to have the ‘expert.’”* Three participants mentioned the professionals’ expertise without associating any positive or negative comments to it. When the expertise was lacking, however, a situation noted by two participants, comments took on an angry tone. For example, one parent said, *“she was terrible. She could maybe write a lovely report but she had no hands-on experience.”* Expertise was expected.

Feelings relating to the diagnostic outcome. Aside from feelings related to the process and the professionals involved in the process, parents brought forward the idea that the entire process and resulting outcomes had felt extremely distressing and at times traumatic to them. They reported worrying, grieving, and feeling guilty. In addition, they discussed the amount of support they felt they received immediately following the diagnosis and related feelings of abandonment.

Deep distress: “Devastating.” Sixty percent of participants brought forward the idea of being deeply distressed, whether in relation to the diagnostic process itself or the eventual diagnosis of ASD. For example, one parent stated that *“in the first few months going through that process we were really upset...”*, and *“we were totally blindsided by (the thought of autism)”*, corroborating that seeking a diagnosis of ASD can be a distressing situation. Another parent indicated that *“having to repeat everything is horrible on parents (...) you're going through trauma and, you know, nightmares and everything else”*, suggesting that a difficult process can have the impact of making a distressing experience more traumatic than need be. One parent summed up what the others alluded to by saying: *“to have a child who is*

autistic is an absolute incredible blow for any family to receive and it doesn't matter how you can spin it back around, it is completely and utterly life-changing."

Four out of ten families reported post-diagnostic worry about their child's future. One parent whose child was diagnosed with a mild form of ASD and average intellectual functioning, which suggests a very good prognosis, still expressed this reaction when she stated: *"fear as parents I guess, to think your child's going to be different. What's in store for him for future? That's my wife's biggest concern. Is he going to be able to grow up and be on his own, hold a regular job and all that stuff? What does the future hold, you know, or what does this mean?"*

Related to this concept was the theme of grief, or grieving. Four out of ten families mentioned they felt they were grieving following the diagnosis. One parent put it well when they stated: *"dealing with, as a parent, the grief and the loss of the child you thought you had, or like the future that child was going to have (...) You are simply going through day by day, dealing with today, because you can't let yourself dream, or you can't let yourself look too far to the future because so much can change in a summer, in a month, in a week."* The magnitude of the emotion was well captured by one participant who said: *"I remember breaking down thinking okay well this is definitely autism then, like you go through all those steps. You're always, you know, you are in denial at first, and then you go through the grieving process. It's the same thing as grieving death; It's a big process that you go through. So I remember going through all that, you know, just holding a child and hoping that this wasn't really happening and you cry a lot."*

Two out of ten families talked about feeling guilty. One parent believed they were responsible for passing on ASD genetically. The other expressed guilt in relation to having missed the signs of autism earlier on in the child's development.

Perceived abandonment: “Kind of got left hanging.” Unfortunately, at this difficult time (when receiving a diagnosis of ASD), forty percent of participants brought forward feelings of abandonment, including the parent who fell in the ADT group. They weren’t always sure when the next service would be initiated. *“You’re left with, well, “what do I do now?” You’re given this news and then you’re just to sit there and wait for help to come, and it doesn’t come. That sucks. It should’ve been diagnosis, then help almost like weeks after.”* One participant who was currently receiving community-based services had this to say: *“the workshops would have been good if once you’re diagnosed, they give them to you right then. Right then. That would have been helpful, but not two years after the fact, because two years after the fact, we’ve learned all that already on our own.”*

Following a diagnosis, parents were not sure who to call or who could answer their questions: *“they really should have followed up with us (...) we haven’t really heard from anybody after that, until recently. I think when you’re left alone to try to figure (it) out, to research it on your own, you’re going to be exposed to everything on the Internet, whether it’s scientifically-based or not. Without someone to have a sounding board off of, you really don’t know what you should and shouldn’t look into and try.”* Professionals who had been very empathetic through the diagnostic process were suddenly perceived as unavailable to them and no longer responding to their calls, given that their responsibility in the process had ended. One parent stated: *“I understand that she wasn’t probably the proper person to advise me on the situation, but it would’ve been nice to just get a phone call and just directed me a little bit. That would have been nice.”* Another parent added: *“after the diagnosis, that’s when you’re left blank. You’re left, ‘okay what do I do now?’ There was not...There should be steps given”.*

Evidence of coping. Dealing with such strong emotions can become overwhelming to parents, and the best outcome for them is to find ways of coping with the reality of the situation. Transformations occur as the family reorganizes around the diagnosis (Watson et al., 2011). Although not a variable in the research design, a coping theme was noted. In this study, agency, gratitude, acceptance, and seeking support were all referenced by the participants. They will be discussed next.

Emerging agency: “Case management.” Possibly to facilitate coping with the perceived lack of information, forty percent of participants reported engaging in case management types of activities such as checking on the status of the referral. Half of those families reported this information matter-of-factly, and the other half reported some associated resentment regarding their new role: “*Thank God I’m very persistent and bitchy and I don’t give up. I got very determined as to how to get her back in-- fast as opposed to having to start all over again.*” Another parent reported: “*We kind of thought (the pediatrician) was going to see him right soon, and so we were really under a misunderstanding of how things are happening, how things were going to work out there, so I kept on asking questions and calling.*”

Aside from the case management roles that emerged during the onset of the diagnostic process, a sense of agency continued post-diagnosis for seventy percent of participants. Although it was mainly referenced in a neutral manner, agency came across in the interviews as reducing anxiety and possibly offering hope. One parent stated: “*I still go through spurts where I start reading a lot about it. I mean, there’s hope. There’s better treatments out there.*” Another talked about her to-do list as a parent: “*the next thing on my to-do list today is to call the Child Care Resources and find out where we are on that list. And then from there, it’s just setting goals for (child’s name) and then my infant care development worker is scheduled to*

check-in in December. So that's where I am with the autism services. When I was given the diagnosis, I was also given the information for provincial and federal funding, so that's all been applied for, that's all been sent out." This emerging agency can be viewed positively by parents if they are not already overwhelmed with other stressors.

Feeling Gratitude: "I'm grateful." Another common theme was gratitude. Eighty percent of participants reported some form of gratitude. Parents were grateful for early detection and comments made to them that helped initiate the diagnostic process: *"if it wasn't for my family physician referring me to Wordplay, I don't know where we would be at, because I don't know if it wouldn't have been caught until he was much older."* Parents were thankful anytime they received a service that helped their child progress: *"We're very very fortunate that (child's name) has come a long way."*

Participants appreciated access to professionals they viewed as experts: *"And again I was so fortunate to have the people that I did."* Finally, they felt lucky and thankful for social supports such as friends, family, and other parents. For example, one participant recalled this event: *"You know, it was the little things. Our neighbor next door, he has a grandson who is autistic. When we were going through (this), we sort of mentioned it in passing that that was what we were exploring, you know. It's amazing; people don't talk about it but when you start talking about it, how many people are affected or whose lives are touched by it. And, you know, a simple act like, he cuts our front lawn for us. He doesn't ask. He just does it, and it's little things like that that, it's like, 'wow', you know? Like, it doesn't have to be a big thing, but those are the acts that I'll never forget."*

Acceptance and support: "A big part of the journey is acceptance." Five of the ten participants gave indications that they had accepted the diagnosis, and the suggestion was that in

accepting the diagnosis, parents were able to embrace services and supports. For example, “*so that was a reality check for the both of us, and we knew that we were going to fight and do what we can (to support him).*” Another participant stated: “*It’s important to admit that maybe that’s what could be wrong.*” Another said: “*Just go (through the diagnostic process), because it doesn’t hurt to get a diagnosis. And then he’s seven now, and he’s in a typical classroom. He has a year and a half of IBI in him so...*” Acceptance and sharing of the diagnosis with others resulted in increased supports available to parents in the form of financial assistance (respite funding, PC Charities, autism-dog), social supports (other parents/grandparents, family) and community resources. Various types of supports were mentioned by eighty percent of participants.

Non-diagnosis

As mentioned earlier, of the initial 12 interviews, two children had not received a diagnosis of ASD. Their experience was predominantly negative, and it was felt that going through the diagnostic process and leaving without a diagnosis may represent a different experience than the one we were attempting to explain in this research. The manner in which their experience differs from that of the larger group will be discussed next.

When parents went through the diagnostic process but left without a diagnosis of ASD, they reported the same types of experiences as parents whose children received a diagnosis, but themes of acceptance were replaced with confusion. A very bitter taste remained following the autism specific assessment, when they were sent on the next wait list or the next set of tests. One parent recalled that following the assessment, “*there was no direction from there on. It was kind of like ‘ok, so you’re back to your pediatrician, see you later.’ I wouldn’t have called them and said ‘okay so where do we go next?’ because it wasn’t relevant anymore. They’re only testing*

him for that and that's it. So I, like, you just said he doesn't have it, so I'm not going to come back to you or question the results that these professionals have said, you know. I don't know what they're watching for, and clearly he didn't meet. And the results were very, very clear: he didn't even come close. He didn't even score for some of them. So he wasn't even slightly close to being on the spectrum from what they saw. But on the other side, on the adaptability skills and the daily functioning, those were very little. So it was kind of like, for us, it was like a catch-22: so he's really smart, but he's not functioning because of the issues he has, but he's not autistic. So what do I do with that?"

For the other parent, the pediatrician delayed testing initially due to his lack of concern about the symptoms. Although this child never received a diagnosis of ASD, the delay impacted the family's ability to cope because they continued to receive feedback from various professionals about their strong beliefs that the child fell on the autism spectrum. The parent stated: *"It's very frustrating because every person that has ever been involved with my son has said the same thing: 'There is no doubt about it that he is definitely a high functioning autistic.'"* Both of the parents who had not received a diagnosis for their child reported negative feelings regarding being faced with contradictions between professionals regarding their child's diagnosis.

Summary of the Experience Shared by Participants in this Study

Keeping in mind that this sample of participants represents mainly the experience of receiving a diagnosis from a single practitioner, a majority of parents struggle when their concerns were not heard, or when hearing concerns presented to them that they had not noticed themselves. Once the diagnostic process has been activated, however, parents are faced with a wait that the majority find frustrating. Information about what to expect during this wait time

may reduce frustration. Many parents develop agency in taking on the case management role during the wait but tend to report on this new role in a neutral manner. Some parents report resentment regarding this new role. Finally, the comprehensiveness of the assessment is noted mainly in a neutral fashion, and at times reported as unpleasant and overwhelming. No positive comments are noted about appointment demands.

Professionals who demonstrate expertise in the area of autism and child development are highly regarded by parents, especially those that take the time to listen to parental concerns, share their knowledge, and respect the parent's own expertise regarding their child. When a parent was the recipient of respectful communications, they felt heard and listened to, hopeful about their child's strengths, and they reported the professional as empathetic. The highest praise was offered to those professionals who were empathetic, non-judgmental, but also knowledgeable.

Regarding their own actions and emotions, parents frequently talked about their successes and failures in coping with the diagnostic process and with the diagnosis itself if it was provided. A majority reported that the process was deeply distressing or traumatic for them. As well, the process elicited feelings of guilt and worry. A positive diagnosis at times led to grief related to the loss of hopes, dreams, and normalcy.

Parents who reported short wait times, access to experts in the field, and fast access to services post-diagnosis presented with the most positive comments. Parents who received multiple diagnoses, waited on multiple concurrent wait lists, had access to professionals they didn't necessarily view as knowledgeable, ultimately had multiple negative comments. Everyone presented comments suggesting that the process and the diagnosis was difficult to cope with, but some parents were also able to talk about their gratitude throughout the process.

Chapter IV: DISCUSSION

The difficult and at times traumatic nature of the diagnostic experience when seeking a diagnosis of ASD has been well documented (Estes et al., 2009; Goin-Kochel, Mackintosh, & Myers, 2006; Hayes & Watson, 2013; Miodrag & Hodapp, 2010; Osborne & Reed, 2008; Watson, 2009). Currently, at the ADT, many of the concerns raised by parents in the Osborne and Reed (2008) study have been addressed for children under six years of age. Prognostic information is provided along with results of the assessment; standardized assessment methods are used, as is best practice. Support services are mentioned at the time of diagnosis and contact information is provided in the report or alternatively, children are directly referred to treatment services following the assessment feedback meeting. Parents are also encouraged to call back and to discuss any questions they may have. This study's main objectives were to partially determine the effectiveness of the multidisciplinary ASD diagnostic process in the Sudbury/Manitoulin region and gain a better understanding of the experience of participating in that process. This chapter reviews the findings in light of previous research, reviews recommendations to help reduce the impact of the diagnostic process on parents, and discusses limitations of the study, concluding with directions for future research.

A More Consistent Experience

In as much as parental satisfaction and reduced wait times were used as variables indicative of partial effectiveness, the results of this study do not permit one to conclude that this multidisciplinary process is more effective. Based on these results, one cannot at this time say that parents of children participating in the ADT are more satisfied or wait less time to receive

their diagnosis than parents who did not follow the ADT process. Overall, both groups reported being satisfied based on quantitative data.

It can be said, however, that the ADT is a more consistent service than was previously available in the region. When a child receives a diagnosis through the ADT, he or she is more likely to have received a comprehensive assessment (i.e., cognitive, adaptive, autism severity) that utilized standardized tools, and he or she likely waited as long as all others going through the ADT process. No child in the ADT group ever experienced the level of variability in service that was once reported in the Sudbury/Manitoulin area, and this is an important accomplishment. Consistency in service between clients, however, has not been a factor treated in previous research on the topic. Nonetheless, this finding is important in an applied, clinical setting.

The comprehensiveness of the assessment process has been brought forward by parents in the literature. In Kerrell's (2001) study of an autism multidisciplinary diagnostic clinic, employing a similar sample size and similar demographics to the present study, clients reported poor satisfaction with their service on a four-point scale. Our community sample, which included parents who participated in the multidisciplinary assessment team and those who received a diagnosis from a single practitioner, were reporting levels of satisfaction in the quantitative component of the study in the "satisfied" range. Participants in the Kerrell (2001) study mentioned a desire for practitioners to spend more time with their child during the assessment. The need for a more comprehensive assessment did not come up as a theme in the current qualitative component of this study. The quantitative study allows us to confirm that a large portion of children referenced in the present study received a comprehensive assessment, either prior to or after receiving an ASD diagnosis. Therefore, by using both sources of information, we can confirm that Sudbury is succeeding, perhaps better than the community

sampled in the Kerrell (2001) study, in providing comprehensive assessments to children who are being considered for or diagnosed with an ASD.

Also, as a community, all children being assessed through the ADT received a comprehensive assessment, and this was not previously the case in the Sudbury/Manitoulin area. This service improvement should also be considered an accomplishment and an important finding from an applied perspective. It is therefore worthwhile to continue providing comprehensive assessments as a community, while being confident that the timing of the assessment does not seem to have an impact on parental satisfaction. Supporting parents through the extra and at times overwhelming demands placed on them during this comprehensive process should be considered. Some parents viewed the demands placed on them as excessive and unnecessary. It may help to offer such parents a clearer picture of the benefits of the assessment comprehensiveness.

Enduring Feelings and Experiences

An analysis of the qualitative data gathered saw themes emerging that were similar to those consistently noted in the research literature. The present sample consisted primarily of parents who had received a diagnosis from a single practitioner but also a few parents who had experienced the ADT. The experience of receiving a diagnosis through the ADT could not specifically be studied because the sample was small and the response rate was low.

The present study noted similar themes to those reported by Dr. Watson (2009) in her doctoral dissertation on the experience of dealing with professionals when seeking a differential diagnosis. Notably, difficulty getting the assessment process started and a sense of abandonment following the sharing of results were noted by participants, including those who had experienced the ADT. Comments regarding professionals' level of expertise and knowledge were noted in

both studies, with parents in the present study reporting a mix of positive and negative comments. The feelings and experiences of going through the diagnostic process are enduring and unfortunately, they continue to tend towards the negative based on results of the qualitative component of the study.

The Mixed-Methods Message Regarding the ADT

This study utilized a mixed-methods approach to compare the ADT to single practitioners. It is not a program evaluation of the ADT because the single practitioner experience was also examined. In addition, the questions asked during this study may have created a volunteer bias toward the negative. That is to say, those parents who had a negative experience may have been more likely to respond to the request to participate in the study. This may in part be responsible for the overall sense of negativity in the qualitative portion of the study as well as the more neutral level of satisfaction noted in the quantitative portion of the study.

One may say that the most important finding in this study is the improved consistency and comprehensiveness of services provided to the region, demonstrated by the data in both the quantitative and qualitative components of the study. Despite the lack of statistical difference between groups on the wait time variables, improved consistency in service delivery is an important accomplishment. Furthermore, parents in the region are not discussing the comprehensiveness of services they received. This concern was not brought forward in the qualitative data. The absence of this theme, along with the quantitative data regarding the comprehensiveness of the assessments provided to our sample, allows us to confirm via this mixed-methods approach that the families in the Sudbury/Manitoulin region are generally receiving the level of comprehensiveness that is recommended.

Finally, the qualitative component of this study, as it mostly represented those parents who received services from a single practitioner, allow us to confirm that information gathered in previous research on the experience of receiving a diagnosis of ASD continues to be relevant, and that decision-makers can remain on their current course of action. That is, they can continue striving to reduce wait times, improve access to experts in the field, and to provide resources to families through the diagnostic process and at the time of diagnosis. It further substantiates the need to provide a more formalized source of support to families at the time of diagnosis, as evidenced by themes presented by parents in both groups. In order to alleviate some of those negative feelings, the combined information from qualitative and quantitative data suggest that parents in this study are interested in specific improvements.

The Type of Team: An Important Difference to Consider

In comparing the present study to results that emerged in the Beatson & Prelock (2002) study of the VT-RAP, one notices general differences, keeping in mind that the number of ADT participants was quite low and that a clear picture of their experience could not be obtained. The VT-RAP was clearly an interdisciplinary team while the ADT is a mix between an interdisciplinary team and a multidisciplinary one. The Sudbury service involves fewer interdisciplinary steps than the project studied by Beatson & Prelock (2002). Such an important difference would explain why ADT parents in the present study continued to bring forward concerns that were noted in the Kerrell multidisciplinary team study regarding the need for support post-diagnosis. At the VT-RAP, parents reported a ‘becoming friends’ theme that did not emerge in the Sudbury ADT data, either in the qualitative interviews or in comments written on the questionnaires. Instead the opposite seemed to be true, with ongoing concerns about lack of support post-diagnosis. The parents in this study at times seemed to be fending for themselves

in that some continued to have difficulty activating the assessment process, needed to take on a case management role to ensure appropriate service delivery, coped with the demands of appointments, and at times needed to defend themselves against professionals who lacked empathy. They certainly did not report feeling supported following the diagnosis, something that is noted by the VT-RAP team. Perhaps the nature of VT-RAP team allowed for all of these conditions to be attended to whereas the primarily multidisciplinary nature of the ADT, although providing greater consistency in service, did not allow for a clear improvement in various factors contributing to overall satisfaction. The results of the VT-RAP study were overwhelmingly positive, and the coupling of assessment and intervention services into one service (i.e., no additional wait time between assessment and intervention) may be the source of this satisfaction. The format of the team is an important determinant of overall satisfaction. The difference between interdisciplinary and multidisciplinary seems to be an important one, and supports the expert clinical recommendations expressed in the Nachshen et al. (2008) Canadian best practice guidelines that interdisciplinary teams should be favoured.

Lessons Learned from Different Diagnostic Paths

Three participants who had been in contact with the ADT process were interviewed as part of the qualitative component of the study. The first participant entered and left the ADT process with a diagnosis, and was included as part of the qualitative analysis. The second participant entered the ADT process but left to have the assessment completed in private practice. They were also included in the qualitative analysis, but their experience could not completely enlighten us about the experience of the ADT. The third and final participant entered the ADT process but did not leave with any diagnosis. Information on the paths taken by these three participants is worthy of discussion.

The participant who did in fact have their child assessed through the ADT and received a diagnosis for their child followed the diagnostic path that was conceptualized when the ADT was created. They heard professionals' concerns about their child's development at a young age, they entered directly into the ADT process while receiving assessments from speech language pathology and the medical community, and the entire process was less than a year long from the point of initial concern. That child is now on the wait list for various services at CCR, including the IBI wait list. The mother has engaged in parent education workshops. Despite this more direct path and seemingly easy access to services, this mother still reported feelings of abandonment following the sharing of the diagnosis. She was not sure whom to contact next. This mother also would have liked a point-person, someone to contact if she had any questions, or simply for support. Despite access to this new community model for the assessment of ADT and relatively low wait times and access to fewer professionals consecutively, this parent continued to feel abandoned at the point following the sharing of diagnostic results. The feeling of abandonment is a strong indicator that there is a gap for parents following the diagnosis, and that it is an important part of the puzzle to help parents cope with the diagnosis. Parents would like access to services and supports, they would like access to resources and written guidelines about what to expect in services and at home with their child over the years.

In turning towards the second participant who left the ADT wait list for an assessment in private practice, the acceptability of the wait time must be examined. When a process is put in place to improve satisfaction, but the wait is excessive and leads to parents aborting the process, then it is difficult to argue that it is a better way of serving the community. Prior to the implementation of the ADT, the combined wait time was estimated at 28 months from the initial intake at Children's Community Network to the time the diagnosis was provided to the family or

the assessment report was shared. The time between first presentation of concerns to a professional was not taken into consideration. For the ADT participants in this study, an improved wait time of 20 months was reported on average. Although no relationship was evident between wait times and satisfaction in the quantitative study, qualitative information suggests a link between small wait times and the expression of positive emotions, and at the very least, a reduction in the use of negative adjectives describing their experience. Sudbury professionals need to continue striving to reduce wait times. One begins to wonder what is an acceptable amount of time to wait for this type of assessment. The Ontario Auditor General's report on autism services acknowledges "early diagnosis and treatment of autism might reduce the need for more supports and services later on in life" (Office of the Auditor General of Ontario, p.55). Unfortunately, no government guidelines exist on the matter of acceptable wait times to investigate the possibility of an ASD and these would be helpful in securing funding to improve services. The government needs to implement guidelines regarding the amount of time that is acceptable to wait for an ASD diagnosis from the time concerns are first presented to the general practitioner. One parent who waited less than a year and a half presented with fewer negative adjectives regarding the wait, and one parent who waited only nine months had nothing negative to say about the wait. This may be a good starting point for administrators.

In the case of the final ADT participant in the qualitative interviews, the issue of non-diagnosis is highlighted. A large percentage of children leaving the ADT do so without a diagnosis because they do not fall on the autism spectrum. The high number of non-diagnosed cases should be of concern to community partners for reasons that include the partners' capacity to refer to appropriate treatment providers or offer appropriate medications. Families that are continuing on their search for a diagnosis are in a state of limbo and require practical and

emotional support in dealing with their children. The ADT was born of necessity to help reduce parental stress and to follow best practice guidelines for diagnosis of ASD (Nachshen et al., 2008). Parents waiting for a diagnosis of autism prefer to deal with fewer professionals consecutively and a shorter wait for a diagnosis: this is true of parents seeking any diagnosis. In her study of parents' search for a differential diagnosis, Watson (2008) found four themes:

These themes included the importance of “knowing” and having a name; knowing the cause for the disability; understanding future expectations; obtaining knowledge regarding appropriate interventions; and gaining access to funding or specific services.
(p.180)

Parents will likely continue to seek a diagnosis following their involvement with the ADT if their child is not diagnosed.

The issue of non-diagnosed participants in cases where behavioural and/or adaptive difficulties are high is quite problematic and the path these parents face is unclear. Upon leaving the ADT, those who are suspected of other mental health difficulties such as OCD, ADHD, tics, depression, or anxiety, will be referred back to their pediatrician for referral to a Psychiatrist or to local children's mental health services for treatment depending on the severity of symptoms. Others will be returned to the central intake mechanism (Children's Community Network) to be redirected to local children's services for further assessment. Still, others already in school may be referred to Speech Language Pathologists in the case of suspected language impairment or to school psychologists when a learning disability is suspected. For many, recommended intervention services are still far away. These children are at risk for never receiving appropriate service, and possibly falling through the cracks. Unless this gap is repaired, this community may never succeed in improving parental satisfaction because nearly half of the users of this service do not receive a diagnosis following their involvement in the ADT.

Future Directions

As a community, we would benefit from attempting to provide a broader assessment service that includes autism when appropriate, rather than an outcome-specific clinic in order to better service a higher number of children and families. Centralized services would allow faster, more comprehensive assessments, and better streamlining to appropriate treatment services. In Sudbury, the Pediatric Centre of Excellence has emerged as a leader in pediatric care. A group of excellent pediatricians has come together to provide a service whereby each can lean on the expertise of the other for difficult cases. A community-based assessment model that would be attached to this Centre of Excellence at the Regional Hospital would be ideal. Modeled after the ADT and the VT-RAP, children could be referred, a thorough intake could take place, and then the appropriate assessment measures could be administered, whether related to autism, learning disabilities, anxiety, depression, intellectual disability, or simply the result of parenting style. The entire process could take place not only under the direction of a psychologist, but also in conjunction with the referring pediatricians and other professionals involved in the child's care.

Strengths and Limitations to the Study

This mixed-methods study was limited to those parents who experienced the diagnostic process in Sudbury/Manitoulin. Information was similar to that found in the research literature, which provides some credibility to the findings. However, the experience of parents who receive an assessment for their child through the ADT may not be transferable to other teams. Non-transferability is especially true given the mixed multidisciplinary/interdisciplinary nature of the team. Also, as the diagnostic process changes and evolves, so does the experience. A replication of this study on participants following the ADT in future would reflect those changes and may not yield results in line with present findings.

There were low response rates for the ADT group in both the quantitative and qualitative studies. Response rates can easily reach 30 to 50 percent for mail out questionnaires (Goyder, 1982). Strategies typically associated with response maximization such as arrangements for follow-ups and incentives (Goyder, 1982) were not deemed acceptable by CCR, given that this population is already under considerable stress. Any sense of obligation or harassment needed to be avoided at all cost. In addition, response rate is said to increase as saliency of the topic increases (Goyder, 1982, p.552). Because the ADT had only been up and running for two years and its effectiveness was the main objective of this study, potential participants who did not follow the ADT process may not have found the topic relevant to them. Also, at the time the study was conducted, the pool of potential candidates who had actually completed an assessment through the ADT was small. Furthermore, between 40 and 60% of children left the ADT assessment process without a diagnosis of any kind (J. Falcioni, personal communication, January 2012), reducing the saliency of the topic of autism for a portion of the potential sample.

It may have been premature to attempt to study the ADT, given it only began completing assessments in 2010. In future, a qualitative study looking at only those parents who have lived the ADT diagnostic experience would allow emergence of themes. Those themes could be compared to those found in the present study to glean improvement.

Given that wait time information was collected retrospectively, data may not be an accurate representation of the actual wait. Attempts were made to minimize the impact of retrospective data by verifying assessment dates in the clinical file. However, it is not possible to verify the date of initial concern.

Satisfaction as a construct has been criticized by researchers as difficult to define, mainly because it is relative to what the person expected (Goin-Kochel et al., 2006) and also relative to

their own experiences (Liu, Amendah, Change, & Pei, 2006; McNaughton, 1994). Given that the parents in the present study could only compare their satisfaction to what they expected to receive as a service and not to what was previously available, it may explain the lack of significant difference between the previous single-practitioner model and the current multidisciplinary team. Furthermore, one wonders if satisfaction per se is even possible given the nature of the experience of determining the presence of a disorder in a young child.

Validation procedures. Rigor is an important consideration in qualitative work. “All theorists agree that rigor is needed in all kinds of research to insure that findings are to be trusted and believed and trustworthiness has been defined as how well a particular study does what it is designed to do” (Watson, 2009, p.140). In this study, four strategies were used to help ensure the rigor of the data and analysis, as suggested by Padgett (1998),(Bowen, 2005). They were prolonged engagement, member checking, peer debriefing and support, and triangulation.

In order to build trust with the participants, the research assistant met with them in their home. There was no time limit to the interview, and the participants were encouraged to continue discussing their experience of the diagnostic process until no new information was being presented. In order to ensure prolonged engagement, additional questions to probe for particularly difficult or helpful facets of the experience were added once the participants stopped offering information spontaneously. The interviews only ended once the participant felt he or she had explained everything they wanted to about the experience.

Member checking was also used as a strategy to ensure rigor. “Member checks require the researcher to verify with the participants any constructions that are developing as a result of data collected and analyzed”(Watson, 2009, p.140). As a part of the interview process, the research assistant was asked to use various levels of reflective listening such as repeating,

rephrasing, paraphrasing and reflecting feelings (Arkkowitz & Miller, 2008). In this way, the research assistant helped validate what each parent was attempting to communicate prior to the end of the interview. Consequently, erroneous constructs were immediately suppressed and the intentions of the comments were corrected. Additionally, the research assistant was asked to take note of any important comments that parents brought forward during the interview in order to provide a summary prior to leaving the home. Nearing the end of the interview, the research assistant summarized her notes for the parents, who immediately had a chance to validate the summary, or add additional comments as necessary. At the end of the study, participants were sent a copy of their transcript (unless they requested otherwise) as well as a list of the themes that were found in the analysis and a narrative summary of the experience based on those themes. They were provided an opportunity to comment on or discuss the findings. One reply was received. Since no concerns were noted, no changes were made to the results.

Following the initial coding of the first transcript, sixty-seven percent of the transcripts were coded independently by both the research assistant and the principal researcher. Seventy nine percent of the codes assigned were the same. Additionally, conversations occurred regarding a code when there was disagreement, in order to ensure the proper code was utilized. The principal researcher eventually reviewed transcripts, handwritten notes and electronic comments provided by the research assistant. Additionally, the thesis supervisor and committee members provided impartial feedback, which lead to the clarification of domains and theme names.

Finally, the data were triangulated. “ In triangulation, researchers make use of multiple and different sources, methods, investigators, and theories to provide corroborating evidence” (Cresswell, 2007, p. 208). Quantitative and qualitative data were both available. Quantitative

data were available on the questionnaire and in the clinical files. Qualitative data were available through the interview process and also when participants made comments on the questionnaire. Along with the transcripts, the research assistant provided notes that were taken in the field, at the time of the interview, further corroborating the essence of the message at the time it was provided. The qualitative data complemented the quantitative data by extending the breadth of inquiry on the experience as a whole, thus providing corroboration and illustration.

Recommendations for Practice

It is unlikely that anything could be done to help avoid the stress associated with the diagnostic experience. However, we have learned some things we could do to help reduce the likelihood that the parent will be strained or further distressed by the process. By drawing on both the qualitative and the quantitative results, a list of recommendations is offered next.

Empathetic and knowledgeable professionals. Practitioners who were viewed as knowledgeable were sought-after, appreciated when available, and missed when not available. Investing in professional knowledge will continue to be important in helping make this process less difficult for parents. Thus, the ADT should continue to value their goal of improving the community's professional knowledge.

Likewise, teaching professionals to truly listen to parents and understand that their child will benefit from professionals listening to their concerns would be very useful. The parent is the expert on their child, and the increasing use of the family-centered approach was also welcomed. The results suggest that parents need professionals to take the time to answer questions that are brought forward, to follow up when requests are made of them, and to respect parental expertise regarding their children. In most situations, even when the child ends up not receiving a diagnosis of ASD, it would benefit the parents and therefore ultimately the children, if any signs

of autism were attended to as soon as they were mentioned. This in itself could reduce wait times for some families, and it is very much in line with the best practice guidelines regarding developmental surveillance (Nachshen et al., 2008).

Challenges to maintaining an empathetic perspective and maintaining knowledge are numerous for professionals in the field of autism. Processes continue to change as governments require them to improve or become more cost effective, often increasing the sheer volume of patients a professional needs to see in a day. The criteria for ASD itself has just undergone a change with the introduction of the DSM-5, making it that much more difficult for those who do not deal with ASD on a daily basis to maintain their knowledge base. The best of professionals still require time to incorporate these changes into their practice, and certain patients may be served during that time, creating the impression there is a lack of knowledge.

Nothing can be gained by ignoring the symptoms of autism. Any professional who sees symptoms of autism should be encouraged to present the symptom as a concern to families and refer them for a comprehensive assessment, so the symptoms can be framed appropriately. We would caution, however, that professionals need to be aware enough of the complexities of posing such a diagnosis that they will not do so without first engaging in a team process. This may lead to professional disagreement on the presence or not of a diagnosis, which was related to the use of negative words in the present study. A lack of confidence was expressed when parents were faced with opposing views regarding the diagnostic status of their child.

Finally, paraprofessionals are gaining in their confidence surrounding autism as well. However, their knowledge should also include awareness of the complexities of the diagnostic assessment for autism. If a paraprofessional speaks with certainty about the presence of an ASD, it could further increase the distress associated with the diagnostic process. It would be

important to teach paraprofessionals to notice abnormal development and point out the symptoms to the parent in the absence of a label. Their increased knowledge of the process as well as respectful communication strategies will also be important, so that they can gently guide parents to appropriate service providers.

Improved parental awareness. Some parents who had concerns about their child's development may have researched autism prior to seeing a professional, as seen in the preponderance of parents who reported emerging agency during the diagnostic process. However, this may not be the case for families who are not suspecting any issues. Parents who had not been suspecting an ASD were particularly perseverative about their difficulty in coping with the diagnostic process and viewed it as traumatic, at times many years following diagnosis. One way to counter this lack of awareness is by highlighting developmental differences in social and communicative behaviours as well as the presence of repetitive behaviours to parents in the absence of a label of autism. Recently, changes have been made to the well-baby visits in Ontario that allow physicians to verify the development of play and communication skills at 18 months of age (Ministry of Children and Youth Services, 2010b). These changes could help soften the blow for many unsuspecting parents by increasing their knowledge of typical development. Improved parental awareness of normal development could increase their readiness to accept their child's deviation from the norm as something that requires further investigation.

Post-diagnostic support. As mentioned previously, parents continued to express concern regarding the lack of support they experience following the diagnostic sharing meeting. This is not a concern that was noted from parents who participated in the VT-RAP (Beatson & Prelock, 2002). It is likely that a variety of steps that were included in the VT-RAP assessment

process provided parents with the support they required. Notably, the VT-RAP included a post assessment planning meeting that allowed parents to meet with all professionals involved with their child as well as community partners to discuss preliminary findings and brainstorm a maximum of five appropriate and achievable recommendations. Then, parents participated in a follow-up meeting with community partners for the purpose of sharing the final report and reviewing recommendations. Given the parents' and communities' collaboration in the formulation of the recommendations, greater adherence was expected. Finally, prior to leaving the clinic, the family was offered a binder containing local resources and contact numbers along with important information about autism spectrum disorders and appropriate intervention strategies. Additionally, the process included the assignment of an assessment coordinator; a person who followed the family through the process from beginning to end. In order to achieve satisfaction levels more in line with those obtained by the interdisciplinary team in Vermont, the ADT would likely need to adopt strategies that help parents feel supported throughout the assessment and beyond. The implementation of a point person to help guide parents through the assessment process and on to intervention services may help alleviate the parent's sense of abandonment following the diagnosis.

Parental suggestions. Explicit and implied suggestions were noted in the data that was provided and gathered for this study. Voiced below is a list of practical recommendations taken from that data and phrased from the parents' point of view:

- Let me explore my concerns, and don't ignore it if you observe symptoms.
- Don't come on too strongly about what might be wrong – check to see what I'm ready to hear.
- Tell me what to expect while I wait.

- Give me a contact name, number while I wait.
- Take the time to listen.
- Find out what I know.
- Don't make me repeat myself.
- Be empathetic
- Give me an expert.
- Share your knowledge, but be kind.
- Offer information about services.
- Offer hopefulness in prognosis
- Provide warmth and compassion when you share bad news.
- Don't leave me hanging following a diagnosis.
- Connect me to a key support person right away.
- Work out arguments with other professionals among yourselves, not with me.
- Don't stop investigating until you know what's going on with my child and you all agree.

Future Research

In order for a true understanding of the diagnostic experience in the ADT to be reached, a qualitative study would need to be conducted once a greater number of children have been diagnosed through that process. Because of the high number of parents who do not receive a diagnosis when completing an assessment through the ADT, it is important to maintain a clear understanding of their experience through the process as well. If the ADT remains as it stood at the time of this study, it would be important to understand what needs to be done to support these families as well.

Although the effectiveness of a multidisciplinary team was not evident based on results of this study, we only examined the parents' perspective on the team. It would be worthwhile to examine the experience of professionals working in multidisciplinary teams to understand the benefits or downfalls of this process. Perhaps professionals in the community are the benefactors of this model. Furthermore, rather than focusing on satisfaction, it may be beneficial to query parental expectations regarding the process and how the process met with those expectations.

There seems to be some added value to interdisciplinary teams that is not evident in multidisciplinary teams. Future research could focus on the difference between the two, especially in light of the added complexity of the former. Specifically, do parents feel greater levels of support when they have a greater sense of who is on the team and what each individual has to offer?

A coping theme was noted in the qualitative component of this study. The study demonstrated that certain families used coping strategies such as agency (or taking action in a case management type of role), acceptance, seeking social and community support, and gratitude. In order to provide improved support following a diagnosis of autism, it would be important to gain a better understanding of why some families use these strategies while others do not, and what can be done to improve a family's coping style. Strengths-based services would benefit from a greater understanding of coping.

Conclusion

Satisfaction and the expression of positive emotions in relation to the diagnostic process may have little to do with the nature of the assessment team, and more to do with other factors. Namely, the amount of time parents wait, the experience they go through while they wait (who they can call, what they know about the process), the expertise available to them during the

actual assessment and the personal characteristics (empathic, non-judgemental, active listeners, warm) of the professional or professionals they are in contact with. In taking into account some of the recommendations of previous research in the development of the ADT, some of the concerns expressed by previous participants in diagnostic processes have been addressed. This might have changed the themes and concerns parents brought forward. However, there continues to be a gap in service that may only be addressed by a true interdisciplinary team that allows the parent to feel supported from the point of initial concern all the way through to the provision of intervention services. The ADT provides a more consistent service to families, both in regards to the amount of wait and the comprehensiveness of the assessment. It is recommended that service providers maintain the comprehensiveness of assessments, offer greater support throughout the assessment process and into the intervention services, and follow-through with the diagnostic workup for children who do not meet criteria for an ASD until a resolution is found by a team.

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Appendix A: Questionnaire (Parental Satisfaction with the Diagnostic Process Survey)

Below is a list of questions to complete. Feel free to make comments. All information will stay confidential.



Your Age: _____ Your Sex: M F
Your Relationship to the child: _____

Note: if you have more than one child with an ASD diagnosis, complete the survey with one child in mind. You can complete one survey per child.

1. What diagnosis did your child receive? Please circle appropriate response.
- ☐ Autistic Disorder - Severe
☐ Autistic Disorder – Moderate
☐ Autistic Disorder – Mild
☐ Autism or Autism Spectrum Disorder
☐ Asperger's Disorder
☐ Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS)
☐ Other diagnosis: please specify _____
☐ No diagnosis
2. Who assessed/diagnosed your child? Please check the correct response.
- | One professional | or | Team of professionals |
|---|-----------|---|
| <input type="checkbox"/> Pediatrician: _____ | | <input type="checkbox"/> ADT (Autism Diagnostic Team) |
| <input type="checkbox"/> Family Doctor: _____ | | <input type="checkbox"/> Other: _____ |
| <input type="checkbox"/> Psychologist: _____ | | |
| <input type="checkbox"/> Psychiatrist: _____ | | |
| <input type="checkbox"/> Psychological Associate: _____ | | |
| <input type="checkbox"/> Other (please list) _____ | | |

3. Using your best guess, how long did the professional(s) spend testing your child before giving a diagnosis? _____

We are trying to figure out how much time it took to get a diagnosis by asking the next three questions:

4. When did you first tell a doctor or other professional you were worried about your child's development?
 _____ (month, year). *If you find this difficult to remember, try thinking back to special occasions (e.g., birthdays, marriages, moves).*

5. When was your child given a diagnosis. When did you feel like it had been decided and shared with you that your child met criteria for that diagnosis)? (You may have received a report that day)

(month, year)

6. When did all the testing stop? _____
(month, year)

7. On a scale of 1 to 5, with 1 being the lowest level of confidence and 5 the most, how confident were you with the diagnosis that was given?

1-----2-----3-----4-----5
Not Somewhat Confident Very Extremely

Parental Satisfaction with the Diagnostic Process (page 2)

8. On a scale of 1 to 5, with 1 being the lowest satisfaction and 5 the highest, how satisfied were you with the diagnostic process overall?

1-----2-----3-----4-----5
 Not Somewhat Satisfied Very Extremely

9. Please place one check mark on the scale for each question.

1 is the lowest level of satisfaction and 5 is the highest:

	Before and during the assessment...	Not 1	Somewhat 2	Satisfied 3	Very 4	Extremely 5
1.	How satisfied were you with knowing what the assessment process would look like?					
2.	How satisfied were you with types of tools used?					
3.	How satisfied were you with the amount of time professionals spent with your child?					
4.	How satisfied were you with how fast the assessment was completed?					
5.	How satisfied were you with how much you were involved?					
	After the assessment...					
6.	How satisfied were you with the way the diagnosis was shared with you?					
7.	How satisfied were you with information you got about what to expect because of the diagnosis?					
8.	How satisfied were you with information you got about what services could help your child and where to get services?					
9.	How satisfied were you with which language was used during the assessment?					

10. What languages are spoken at home? _____

11. Did you receive service in the language of your choice? Y N

12. How could the service be better for you and your child? Would you like to add any other comments? (feel free to add comments on the back of this page if you need more space).

13. Please check the correct option: We are currently: ___ waiting for service, ___ receiving service.

Comments: _____

Your family's circumstances may influence your satisfaction. These questions will help determine what factors are related to level of satisfaction.

Race/ Ethnicity: _____

Parental Satisfaction with the Diagnostic Process (page 3)

Marital Status: Married or living with significant other ☐
 Family without spouse ☐

Level of School Completed:

	Mother	Father
Grade 7 or less	<input type="checkbox"/>	<input type="checkbox"/>
Grade 9 or 10	<input type="checkbox"/>	<input type="checkbox"/>
High School	<input type="checkbox"/>	<input type="checkbox"/>
1 yrs college or university; specialized training	<input type="checkbox"/>	<input type="checkbox"/>
College or university graduate	<input type="checkbox"/>	<input type="checkbox"/>
Graduate degree (MA, PhD)	<input type="checkbox"/>	<input type="checkbox"/>
Occupation	_____	_____

What is your current household income?

Under \$20,000	<input type="checkbox"/>	\$60,000 - \$79,999	<input type="checkbox"/>
\$20,000 - \$39,999	<input type="checkbox"/>	\$80,000 - \$99,999	<input type="checkbox"/>
\$40,000 - \$59,999	<input type="checkbox"/>	over \$100,000	<input type="checkbox"/>

If you chose to participate by providing access to your child's profile, please complete the section below. We need your child's name and date of birth to find the file.

Child's Name: _____ Child's Date of Birth: _____

I, _____, give permission to Child Care Resources to share the personal information of the child named above consisting of a clinical file for the purpose of gathering referral and intake information, psychological assessment report and data (assessment dates, feedback meeting dates, IQ, adaptive skills and severity levels, service status) for use in a research project related to satisfaction with the diagnostic process by Lynn Laverdiere-Ranger.

I understand the purpose for disclosing this personal information to the person noted above is to add to and supplement information given in this survey.

I understand that I can refuse to sign this consent form.

☐ I consent to participate in this portion of the research project (joining child specific information to survey results).

My Name: _____ Signature: _____
 Date: _____

☐ I am interested in completing the interview portion of this research project. I can be reached at the following number: _____

☐ Please **do not** contact me for an interview.

Appendix B: Parent Consent Form



I agree to participate in the research project called “*Parental Satisfaction with Diagnosis of Autism Spectrum Disorders Based on Single Versus Team Practitioner Model*”. I understand the goals of this research project. Lynn Laverdiere-Ranger, Dr. Terri Barriault, Dr. Cynthia Whissell, and Dr. Shelley Watson want to find out about parental satisfaction with the current and earlier models of diagnosing ASDs in the Sudbury/Manitoulin area. Results will shape the service and help CCR better meet the needs of families. I know that I do not have to participate in this study. I can leave this study at any time. It will not affect my service.

All participants who agree to take part in the study will complete a survey. I realize I can participate in two other ways. I can allow access to my child’s clinical file for information about his or her assessment results (age, diagnosis, cognitive ability, adaptive ability, severity of symptoms, service status). I can also volunteer to participate in an audio-recorded interview. This interview will last about thirty minutes. A research assistant will ask me about my experience in the diagnostic process. If the interview is distressing, the interviewer will help me cope with that.

I am aware that the researchers will only use information for research purposes. I know that information will be confidential. My child and I will not be identifiable. A number will be assigned to my data. All personal information collected will be private and confidential. It will remain securely stored in a locked cabinet at Child Care Resources until the end of the study. I can ask for a copy of my interview transcript. I can receive a summary of the results of the study.

If I have any questions or concerns about this study, I can call Lynn Laverdiere-Ranger or Dr. Terri Barriault at 705-525-0055

If I have concerns about the ethics of the study, I can contact Jean Dragon, Research Officer at 675-1151, ext 3213 or at 1-800-461-4030. I can also contact the Research Advisory Committee at Child Care Resources at 705-525-0055.

For parent support and resources in the event you do not want to contact the researchers, consider contacting the Sudbury Chapter of Autism Ontario at 222-5000 x2685

Check all that apply:

- ☐ I consent to completing the **survey** portion of this study.
 - ☐ I consent to joining my **child’s specific information** to the survey results
 - ☐ I consent to participating in an **interview** portion of this research project. I can be reached at the following number: _____
 - ☐ Please do not contact me for an interview.
 - ☐ I would like a copy of my interview transcript.
 - ☐ I would like to receive a summary of the results of this study
- Email address: _____

Printed Name: _____

Signature: _____ Date: _____

Appendix C: Introductory Letter

Dear parent,

My name is Lynn Laverdiere-Ranger. I work at Child Care Resources. I am studying to complete a Master's degree in Applied Psychology at Laurentian University. I am working with Dr. Terri Barriault, Dr. Shelley Watson, and Dr. Cynthia Whissell.

I am writing this letter to offer an opportunity to participate in a research through Laurentian University. This study examines parental satisfaction with the diagnostic process. The research team is recruiting parents of children who have gone through this process.

To participate, complete the attached survey and return it in the envelope provided. You can also participate in two other ways. The second way you can participate is by giving the research assistant permission to look at your child's clinical file, if one exists at Child Care Resources. A research assistant will then add your child's specific information to your survey information. Finally, you can offer to complete a thirty minute interview about the process you went through. This interview will be recorded by a digital audio recorder.

Dr. Watson has completed similar research with some of you. Our current research has a different focus. Our goal is to understand the impact that a team approach has on service delivery compared to service received when a child is diagnosed by a single practitioner. Your participation in this study will help shape services in the Sudbury and Manitoulin area. It will help determine if a team approach is more satisfying for parents than a single practitioner approach. It will help determine if wait times are getting longer or shorter. If you choose to complete the interview, you will have a chance to share your thoughts and feelings on the subject.

You do not have to participate in this study. Your non-participation will not affect the service you receive or plan on receiving from Child Care Resources. Your participation or non-participation will not be known to myself or those who provide service to you.

If you are interested in contributing to a better understanding of parental experiences with the diagnostic process, please read and complete the attached consent form and survey. Thank you in advance for your time and help.

Sincerely,

Lynn Laverdiere-Ranger, M.A.

Name of Study: *Parental Satisfaction with Diagnosis of Autism Spectrum Disorders Based on Single Versus Team Practitioner Model.*

Location: *Sudbury and Manitoulin District*

Eligibility Criteria: *Parents or guardians who participated in the diagnostic process for ASD.*

Lead Investigator: *Lynn Laverdiere-Ranger*

Sponsorship: *Child Care Resources, Health Canada, Société Santé en français*

Contact Information: *Dr. Terri Barriault, Clinical Director, CCR; phone: (705)525-0055*

Appendix D: Ethics Approval



APPROVAL FOR CONDUCTING RESEARCH INVOLVING HUMAN SUBJECTS Research Ethics Board – Laurentian University

This letter confirms that the research project identified below has successfully passed the ethics review by the Laurentian University Research Ethics Board (REB). Your ethics approval date, other milestone dates, and any special conditions for your project are indicated below.

TYPE OF APPROVAL	New	Modifications to project	X	Time extension
Name of Principal Investigator and school/department	Lynn Laverdiere-Ranger (Cynthia Whissell; supervisor) — Laurentian University (Psychology)			
Title of Project	<i>Parental Satisfaction with Diagnosis of Autism Spectrum Disorders Based on Single versus Team Practitioner Model</i>			
REB file number	2011-09-13 R1			
Date of original approval of project	November 29 th 2011			
Date of approval of project modifications or extension (if applicable)	April 4 th 2012 (R1)			
Final/Interim report due on	November 29 th 2012			
Conditions placed on project	Final or interim report on November 29 th 2012			

During the course of your research, no deviations or changes to the protocol, recruitment or consent forms may be initiated without prior written approval from the REB. If you wish to modify your research project, please complete the appropriate [REB form](#).

All projects must submit a report to REB at least once per year. If involvement with human participants continues for longer than one year (e.g. you have not completed the objectives of the study and have not yet terminated contact with the participants, except for feedback of final results to participants), you must request an extension using the appropriate [REB FORM](#).

In all cases, please ensure that your research complies with the [Tri-Council Policy Statement \(TCPS\)](#). Also please quote your REB file number on all future correspondence with the REB office.

Congratulations, and best of luck in conducting your research.

Jean Dragon Ph.D. (Ethics officer LU) for Susan James Ph.D.
Acting Chair of the *Laurentian University Research Ethics Board*
Laurentian University

Appendix E: Summary of Themes

Domain	Theme Name	Parental Quote
The process	1. Difficulty activating the assessment process:	<i>"The first one that brings that up"</i>
	2. Concerns regarding the wait	<i>"A lengthy process"</i>
	3. Appointment demands	<i>"We went to six appointments"</i>
The professionals	4. Respectful communication: How well professionals listened to parents	<i>"Take the time to listen"</i>
	5. Respectful communication: Share your knowledge, but be kind	<i>"How it's going to turn out"</i>
	6. Professional expertise	<i>"Autism specialists"</i>
The emotions	7. Deep distress	<i>"Devastating"</i>
	8. Perceived abandonment	<i>"Kind of got left hanging"</i>
Coping	9. Emerging agency	<i>"Case management"</i>
	10. Feeling gratitude	<i>"I'm grateful"</i>
	11. Acceptance and support	<i>"A big part of the journey is acceptance"</i>